State Level Health Information Exchange Initiative

Development Workbook

FORE
Foundation of Research and Education of AHIMA

A Guide to Key Issues, Options and Strategies

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State-Level Health Information Exchange Initiative Development Workbook

Introduction

Most healthcare information today is fragmented and either on paper or held in electronic "silos" with little interoperability.[2] Fragmentation, in turn, contributes to errors,[3] duplication,[4] lack of coordination between providers, and many other problems.[5] Major improvements to health care quality and safety will require the widespread application of information technology (IT) to provide physicians with immediate and effective access to both information about individual patients and current medical knowledge at the point of care.[6] The report of the Commission for Systemic Interoperability succinctly summarizes the need for a nationwide electronic healthcare information system to provide the appropriate patient information when and where needed and further characterizes it as a "matter of life and death."[7] Furthermore, some estimates of the savings in

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[2] Steve Lohr, "Road Map to a Digital System of Health Records," *New York Times*, Health Section, January 19, 2005; D. Brailer, "Interoperability: The Key to the Future Health Care System," *Health Affairs* Web Exclusive, January 19, 2005; Center for Information Technology Leadership, "The Value of Healthcare Information Exchange and Interoperability," *Health Affairs*, 2004.

[3] Many medical errors are due to the lack of health care information. See L. Kohn, J. Corrigan, and M. Donaldson, "To Err is Human: Building a Safer Health System," Committee of Health Care in America, Institute of Medicine, Washington, D.C.: National Academy Press, 2000; HealthGrades, "In-Hospital Deaths from Medical Errors at 195,000 per Year, HealthGrade Study Finds," July 27, 2004; Health Research Institute and Global Technology Center, "Reactive to Adaptive: Transforming Hospitals with Digital Technology," PriceWaterhouseCoopers, 2005; Peter Smith, et. al., "Missing Clinical Information During Primary Care Visits," *Journal of the American Medical Association*, February 2, 2005, 293:565-71; *Annals of Family Medicine*, July/August 2004; Committee on Quality of Health Care in America, "Crossing the Quality Chasm: A New Health System for the 21st Century," Institute of Medicine, Washington, D.C.: National Academy Press, 2001; D.W. Bates, A.A. Gawande, "Improving Safety with Information Technology," *New England Journal of Medicine*, 2003; 348:2526-34.

[4] This lack of information also leads to tests, and even procedures, being repeated unnecessarily. See Center for Information Technology Leadership, "The Value of Healthcare Information Exchange and Interoperability," *Health Affairs*, 2004.

[5] D. Brailer, "Interoperability: The Key to the Future Health Care System," *Health Affairs* Web Exclusive, January 19, 2005.

[6] William A. Yasnoff, et. al., "A Consensus Action Agenda for Achieving the National Health Information Infrastructure," *Journal of American Medical Informatics Association*, 2004; 11: 332-38; National Research Council, Computer Science and Telecommunications Board Networking Health, "Prescriptions for the Internet," Washington, D.C.: National Academy Press, 2001; National Committee on Vital and Health Statistics, "Information for Health: A Strategy for Building the National Health Information Infrastructure," November 15, 2001; Institute of Medicine, "Fostering Rapid Advances in Health Care: Learning from System Demonstrations," Washington, D.C.: National Academy Press, 2002. P. Aspden, J.M. Corrigan, J. Wolcott, S.M. Erickson, eds., "Patient Safety: Achieving a New Standard for Care," Washington, D.C.: National Academy Press, 2003; D. Brailer, "Interoperability: The Key to the Future Health Care System," *Health Affairs* Web Exclusive, January 19, 2005.

[7] www.endingthedocumentgame.gov

healthcare expenditures from the adoption of interoperable health IT and the secure exchange of healthcare information are significant.[8]

With the promise of improving the quality and safety of healthcare and reducing costs, various government agencies and private sources have been funding efforts to establish data-sharing or health information exchange (HIE) communities. In April 2004, those efforts were further bolstered by President Bush's directive for widespread adoption of interoperable electronic health records (EHRs) by 2014. By Executive Order, he established the Office of the National Coordinator for Health Information Technology (ONC) in the Department of Health and Human Services (HHS). This office is designed to facilitate the development and adoption of a nationwide health information network. It is envisioned that this will be accomplished through the linkage and interoperability between and among local and/or statewide HIEs across the nation.

Local or regional efforts to share healthcare data electronically among stakeholders have had varying degrees of success. Although enthusiasm for HIE continues to grow, even the most successful efforts struggle with organizational, financial, legal, technical, policy, and operational challenges. More recently, statewide initiatives are being launched. State governments, as major employers and payers, are turning their attention to reducing costs and improving the health of their residents through the creation of HIE initiatives. These efforts have been diverse and have been marked by varying degrees of state government involvement. State-level efforts are at a critical juncture, because nationwide interoperability will not be achieved and the currently fragmented healthcare system will continue unless development of these statewide efforts are harmonized and are coordinated with the nationwide agenda to enable the (NHIN). Guidance on good practices and models, with an eye toward achieving nationwide interoperability, is essential to avoid unnecessary duplication of efforts and to facilitate consistency across the states, to the extent possible.

The role and development of what we will call the state-level HIE initiative are the focus of this workbook, which is designed as a practical tool to help those involved in developing and managing a state-level HIE initiative. It provides guidance on some of the issues, options and strategies to consider when developing, a state-level HIE initiative.

Research Project Overview

This workbook was developed as part of the research project conducted by the Foundation of Research and Education (FORE) of the American Health Information Management Association (AHIMA)—under contract to the ONC—to develop practice and policy guidance for state-level HIE initiatives in the areas of governance, structure, operations, financing, and HIE policies.

This workbook is a compilation of knowledge and guidance resulting from this research project titled "State-Level RHIO Models and Best Practices." In that six-month project, a representative sampling of state-level HIE initiatives was engaged and studied. States included for in-depth site visits in the study were California, Colorado, Florida, Indiana, Maine, Massachusetts, Rhode Island, Tennessee, and Utah. A Steering Committee was formed, consisting of leaders from the nine states studied. Technical advisors, project staff, and ONC were also involved in committee activities. The project involved: (1) gathering information about current policies and practices of the sampled state-level HIE initiatives in the areas of governance, structure, financial model,

[8] Center for Information Technology Leadership, "The Value of Healthcare Information Exchange and Interoperability," *Health Affairs*, 2004.

HIE policies, operations, and short- and long-term priorities; (2) convening the Steering Committee and technical advisors to develop consensus on principles and recommendations for state-level HIE initiatives in these areas; (3) convening a national consensus conference to obtain feedback on the draft principles and recommendations (4) producing public domain findings and guidance for developing state-level HIE initiatives; and (5) developing a plan for dissemination and encouraging adoption of the consensus principles and guidance.

The consensus of the Steering Committee, technical advisors, and project staff regarding development of a state-level HIE initiative is reflected in this workbook. The final report for this research project is also available to the public and will include not only this workbook but also other information gathered during this research project, a description of key findings, and recommendations for policies, practices and strategies to advance state-level HIE and the effective role of states in the nationwide health information agenda.

Audience

This workbook is designed for individuals interested in or already involved in a state-level HIE initiative and policy makers who are considering how to guide their state in improving healthcare and lowering costs through HIE. This audience includes individuals from state agencies and state legislatures, as well as providers, payers, employers, and other stakeholders who have an interest in the statewide sharing of health information. This workbook is intended to help focus, enhance, and organize your approach to developing a state-level HIE initiative.

Using This Workbook

This workbook begins by outlining the vision and need for state-level HIE initiatives. The remainder of the workbook is organized into sections that correspond to a set of activities or processes explained further under the "Process for Developing the State-Level HIE Initiative" section. Workbook sections for each process include: guiding principles (where applicable), worksheets and checklists referenced for self-assessment, a discussion of pertinent issues, and examples of some states' practices (where useful). The examples used in this workbook are not intended as an endorsement of any particular practice but rather serve as illustrations of how a practice could be implemented. Appendix A summarizes the findings from the research project on the activities of the nine sampled state-level HIE initiatives, which can serve as effective case studies for states just beginning the development process. Appendix B contains the various worksheets referred to throughout the sections, which can be printed off separately for ease of use. Appendix C contains a table comparison of governance composition for the nine state-level HIE initiatives studied.

Note that the scope of this workbook is limited to the topics reviewed under the research project. It does not address every issue organizers will face. This workbook should be read and used in conjunction with other resources and expert input. Any references and recommendations related to legal issues should not be construed as legal advice, and legal counsel should be consulted to ensure compliance with applicable laws and regulations.

Definitions

For the purposes of this workbook, the following words are defined as follows:

- AHIC—the American Health Information Community (http://www.hhs.gov/healthit/ahic.html). The Community is a federally chartered commission and will provide input and recommendations to HHS on how to make health records digital and interoperable, and ensure that the privacy and security of those records are protected, in a smooth, market-led way.[9]
- HHS— the United States Department of Health and Human Services (http://www.hhs.gov/)
- HIE—health information exchange, which could include the exchange of clinical data, administrative data, or both
- NHIN— the Nationwide Health Information Network. As a key element of HHS's health IT (HIT) strategy, the development of an NHIN will provide the foundation for an interoperable, standards-based network for the secure exchange of healthcare information.[10]
- ONC—Office of the National Coordinator for Health Information Technology (http://www.hhs.gov/healthit/), which is part of HHS. ONC serves as the HHS Secretary's principal advisor on the development, application, and use of HIT; coordinates the HHS HIT programs; ensures that HHS HIT policy and programs are coordinated with those of other relevant executive branch agencies; to the extent permitted by law, develops, maintains, and directs the implementation of a strategic plan to guide the nationwide implementation of interoperable HIT in both the public and private healthcare sectors to reduce medical errors, improve quality, and produce greater value for healthcare expenditures; and coordinates outreach and consultation by the relevant executive branch agencies with the public and private sectors.[11]
- State-Level HIE Initiative— an HIE initiative or organization that is statewide in scope and involves some form of public-private collaboration, partnership, or governance. State-level HIE initiatives take various organizational forms, according to their scope of work and their origin. These are explored in this workbook.

[9] http://www.hhs.gov/healthit/ahic.html
[10] http://www.hhs.gov/healthit/NHIN_Forum1.html
[11] http://www.hhs.gov/healthit/mission.html

NHIN Vision and Need for State-Level HIE Initiatives

Vision

The vision for the NHIN is to improve the quality of care, increase efficiency and reduce costs, facilitate research, and support public health through the sharing of electronic health information securely between stakeholders while protecting patient privacy. State-level initiatives have similar goals for the sharing of data within a state, with neighboring states, and eventually nationwide. It is envisioned that the state-level efforts would enable and/or comprise the NHIN.

Definition

For the purposes of this workbook, a state-level HIE initiative is an HIE initiative or organization that is statewide in scope and involves some form of public-private collaboration, partnership, or governance. The Steering Committee defined the concept broadly enough to cover the varied activities a state-level HIE initiative could do but narrowly enough to differentiate the state-level HIE initiative from other HIE efforts in a particular state. The key difference is "statewideness": state-level HIE initiatives carry out functions best done by a single entity at the state level.

Need for a State-Level HIE Initiative

What is the interest in promoting statewide HIE organization and activity, and why is the state level of organization important in addition to national, regional, and/or local efforts? What can a state-level HIE initiative do that a local HIE effort may be unable or ill equipped to accomplish? The answer to these questions lies in the key role that the state-level HIE initiative can play in creating an environment for collaboration, coordination, and sharing of valuable information among stakeholders, state government, and/or local HIE efforts in the state (see the "Role of the State-Level HIE Initiative" section). The state-level HIE initiative can also play an integral role in balancing the rights and needs of all residents with the imperatives of an efficient system while ensuring that statewide barriers to HIE are removed or mitigated through state-level policy changes. The statewide scope of these initiatives assumes a responsibility for the interests of all state residents, including the underserved. In addition, there is a fundamental mandate for a state to create uniformity, to adopt nationally recognized standards and to function as a connection among state government, local HIE efforts, other states, and the NHIN. A state-level HIE initiative can reduce duplication of effort in local HIE efforts, ensure knowledge is shared across local HIE efforts to facilitate learning from each other, and convene the local HIE efforts and statewide stakeholders to enable constructive dialogue and coordination. The involvement of state government in the public-private partnership places the state-level HIE initiative in a unique position of being able to facilitate statewide HIE policy and related legislation, enable statewide process changes, and have the influence and leverage necessary to carry through on the organization's goals.

Process for Developing the State-Level HIE Initiative

Getting Started

The key to success in developing a state-level HIE initiative is maintaining the vision: the appropriate sharing of healthcare information while protecting patient privacy. Although this workbook breaks out decisions and tasks related to many activities, **it is crucial to focus on doing the real work of HIE and developing a business plan that will sustain it**. Governance should not consume significant resources at the expense of other activities. Many of the activities can be accomplished on parallel tracks.

Depending on where a state begins and what the historical relationships of the stakeholders are, the process of convening and achieving consensus could be relatively short or very long. Key points to keep in mind include:

- Start by securing a circle of key supporters and develop a vision.
- Consensus of all stakeholders is not necessary before beginning; only a critical mass is required to implement HIE.
- It is better to target smaller scale projects for early wins and to demonstrate the value of the state-level HIE initiative, which will also allow the parties to adjust to the (possibly) new concept of collaborating and begin to build trust in the state-level HIE initiative as a neutral convener.
- Open communication among stakeholders is important to ensure everyone understands the implications of the HIE model and is comfortable with participating.

Key Activities

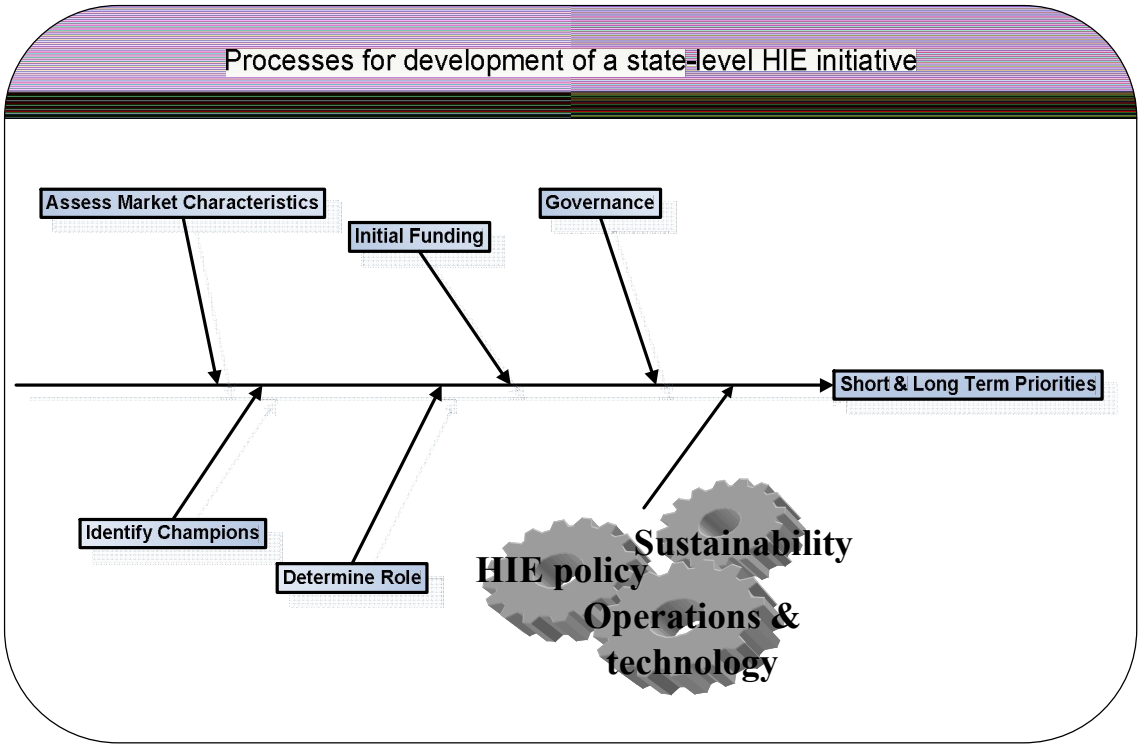
The recommended approach to developing a state-level HIE initiative involves a series of processes or activities. This workbook is organized around these topics and activities.

Activity 1: Assess Market Characteristics
Activity 2: Identify Champions and Key Stakeholders
Activity 3: Determine the Role of the State-Level HIE Initiative
Activity 4: Establish Governance Structure
Activity 5: Obtain Initial Funding
Activity 6: Concurrently Develop Financial Model for Sustainability, Formulate HIE Policies, and Set Up Operations and (if applicable) Technology
Activity 7: Identify Short- and Long-Term Priorities
Activity 8: Reassess Original Assumptions and Plans Often, Expect Change, and Adjust Accordingly

Figure 1 depicts these processes, which do not necessarily occur sequentially. For example, initial funding may be available before governance is established. Note that the interconnected gears in ***Figure 1*** represent the three activities of HIE policy development, financial sustainability, and operations and technology. This graphic is meant to symbolize the interdependence of these three activities. For example, a change in HIE policy may necessitate a change in software and operational procedures, which would cost money and potentially affect sustainability models.

Note also that ***Figure 1*** represents the culmination of the various activities into the formulation of short- and long-term priorities for the state-level HIE initiative. Activity 8, which is not shown in ***Figure 1***, is simply the process of revisiting one or more of the activities periodically, as circumstances change, to reassess or redirect, as appropriate.

Figure 1.



1. Assessing Market Characteristics

Market characteristics can drive what role the state-level HIE initiative will play to further the state's overall HIE efforts. Therefore, it is important to understand the state's market characteristics and assess their potential effect before deciding on the role or any other function of the state-level HIE initiative.

Tasks

1. Document the state's market characteristics. (***Worksheet 1-1 in Appendix B***)
2. Assess how the market factors influence the role, activities, services, and products of the state-level HIE initiative.

Discussion

Worksheet 1-1 in Appendix B is meant to serve as a starting list of market characteristics to evaluate for a particular state. It is not an exhaustive list, and the user is encouraged to add more. After obtaining the factual answers, the potential effect of the market characteristic should be considered.

For example, a state where an electronic system already exists to deliver laboratory results to clinicians would not likely be in need of a new clinical messaging system developed by the state-level HIE initiative. This situation may, however, open up possibilities for the state-level HIE initiative to collaborate with those who already have the clinical messaging system to expand the uses of such a system.

Another example would be a state having limited or no local HIE efforts under way. In such a case, the state-level HIE initiative may choose to develop and operate the technology for a statewide HIE system. However, a state having multiple, local HIE activities in some stage of development would more likely serve as a coordinator or in a convening role rather than conducting technology operations itself.

Market characteristics will be not only useful in defining the role of the state-level HIE initiative and what services or products it can offer, but also important when evaluating financial models and governance and determining short- and long-term priorities.

2. Identifying Champions and Key Stakeholders

Identify strong champions who understand why statewide HIE is important, who have stature in the various stakeholder communities, and who can help facilitate stakeholder consensus. These persons should be well respected among healthcare stakeholders and viewed as people who will put the state-level HIE initiative's success ahead of personal motivations. Identifying key advocates in and among stakeholder groups is important to enhance the likelihood of stakeholder buy-in. Having a clear understanding of what may be sparking or catalyzing interest in statewide HIE will enable the champions to recognize and seize windows of opportunity for advancing the effort.

Tasks

1. Identify one or more strong champions for state-level HIE initiative. (***Worksheet 2-1 in Appendix B***)
2. Engage the champions to move the process forward.
3. Identify key stakeholders. (***Worksheet 2-1 in Appendix B***)
4. Identify key advocates within the stakeholder groups to enhance the likelihood of stakeholder buy-in. (***Worksheet 2-1***)
5. Understand and capitalize on any triggering events, calls to action, or drivers of the formation, advancement, and progress of the state-level HIE initiative. (***Worksheet 2-2 in Appendix B***)

Discussion

The most common sources for identifying champions are listed below; however, there are many more stakeholder sources that have individuals who could serve as champions.

- **Governor or governor's office.** Governors have a unique ability within their states to convene stakeholders, create through executive orders and legislative agenda appropriate organizational and financing structures, and they can mandate internal coordination among state agencies. They also coordinate intra-state activities through the federal government, the National Governors Association, and many other regional and national bodies.

- **State legislators.** Legislators can play a critical role in modifying legislation and engaging their communities. They also serve as a vital link between their constituents and the state government. Legislation to fund access and to maintain an environment conducive to HIE requires an educated legislature that understands the critical role health information technologies play in health care delivery and in regional and state economies.

- **Hospitals or integrated delivery networks or hospital associations.** Hospitals are a nucleus for technology and innovation. Larger systems and delivery networks can provide vital resources for the common good and, by working together, elevate standards for quality and service. Through agreements on standards, they can converge to lower the cost of providing care to patients across institutional boundaries. Competition among hospitals remains, but it is over quality, not possession of data. Smaller hospitals and critical access hospitals have less capital and fewer human resources but nonetheless are vital foundations to the care of their communities. Health information exchange and interoperability should lower overall costs for continuity of care and provide a broader network of services previously unavailable to these organizations and their communities.

- **Medical research organizations.** Medical research organizations are charged with a deeper understanding of our current health care delivery system and technologies as well as the creation and study of new therapeutic approaches and processes to improve care. Such activities are critically dependent on accurate patient information. Although the use of such information must be carefully regulated and endorsed by the individual and the community, the potential to shorten the time from innovation to broad delivery is significant. Examples of such potential are in the use of clinical data to develop more effective post-market drug surveillance, stronger clinical trial enrollment, and a better understanding of the treatment of chronic illness.

- **Quality or patient safety organization or Quality Improvement Organization (QIO).** These organizations are charged with the collection of data to monitor the quality of care delivered by individuals and institutions. Although some criteria for such quality measures are available, there is a consensus that more comprehensive clinical data can improve the way providers and the public measure the outcomes and processes associated with their care.

- **Physicians, medical practices, or medical society.** Adoption of health information technologies by physicians is hampered by a lack of "certified standards," insufficient understanding of how to introduce new information technologies into busy office practices, lack of capital and financing, and an infrastructure incapable of supporting medical care by making pharmacy, laboratory, and other clinical information more readily accessible. Progress in these areas - recently demonstrated through state and federal efforts - will have a strongly positive impact on physicians, other care delivery professionals, and office staff as they try to improve the quality of care they deliver.

- **Pharmacists and other health care professionals.** The true value of health information technology extends beyond the physician practice and hospital and into the community through pharmacies, home health agencies, nursing homes and many other professional groups or organizations. As states understand their regional and state-wide health care programs, they increasingly see the opportunity for HIE to integrate care across these diverse settings.

- **Employers or business groups.** Employers large and small see health care costs and chronic illness impact both the productivity of their work places and their very financial sustainability. To understand how to create the greatest possible clinical value for their health care expenditures, employers are looking for innovative ways to work with their employees to understand the financial and social consequences of illness and its treatment and to create new means of both financing acute care and preventing chronic illness. These approaches require systematic clinical information across a wide range of care settings over an extended period of time. Stronger HIE initiatives promise to create such opportunities for employees and their employers.

- **Health Plans.** Health plans play a crucial intermediary role in managing health care delivery products and services. Traditionally their activities have been limited by their data sources. Working only with their clinical and administrative claims data, health plans have done much to improve the delivery of health care. But much more can be accomplished if plans were in possession of clinical data for their beneficiaries. As is the case in practice settings, the value of such data is unquestionable, but the exchange of data across traditional competitive boundaries is a relatively new experience vital to the evolution of a consumer-focused health care system but challenging in its evolution from traditional plan models to newer and more innovative programs.

- **Medicaid agencies.** Medicaid agencies face a crisis unparalleled in their 40 year history. Over these decades, each agency has specialized its programs and evolved "silos" of information that increase costs and complexity. With the introduction of new and innovative Medicaid reform programs and new computer architecture (MITA) to support these programs, it is important that Medicaid programs be integrated into state-level activities as a seamless part of a state-wide care infrastructure and not as a separate "technology silo" that cannot interoperate with other clinical systems.

- **Department of Health.** State, county, and metropolitan departments of health suffer from high costs for data acquisition, incomplete collection of information on vaccinations and other critical health care needs, and a high degree of difficulty in bringing this information into the hands of the appropriate individual. By integrating into a health information exchange, these Departments would be able to collect more data automatically and ensure both more timely analysis and secure and confidential reporting to affected individuals.

- **Other state agencies with health-related missions.** Many state agencies - directly or indirectly - are involved with health care or could benefit from the technologies and policies developed as part of a state-wide HIE. Prison systems incur high health care costs and the effective transfer of prisoners with chronic disease into the community is imperfect at best. School systems are ideal loci for disease prevention and education and in some instances may play a greater role in vaccination and other treatment programs. If the privacy and security challenges essential to the success of health information exchange can be generalized, such a system provides great opportunities for such organizations both to collect appropriate information, convey such information when consistent with the request of the individual, and to make use of this information in counseling and treatment.

- **Health technology leaders.** Although the leaders in both health care technology and its clinical adoption are primarily focused on developing and effectively using information

systems meeting the acute, internal needs of their organizations, the opportunity for states to convene such individuals to educate one another and to address common approaches to complicated technical and policy problems presents great opportunities to improve the health of the entire community and lower the marginal cost of technologies for all participants

Worksheet 2-1 in Appendix B provides a listing of potential HIE stakeholders, along with space to identify specific organizations and individuals for each stakeholder group, along with the status/feasibility of their involvement. It can be utilized to identify and track sources for champions for the state-level HIE initiative.

The following is a sample list of possible triggers or drivers to action:

- Governor's Executive Order
- Legislative mandate
- Grant or other money available for statewide HIE
- Summit or ongoing meetings of healthcare leaders
- Medicaid crisis
- Local leadership impetus
- Self-interest of the organizations seeking value and return on investment
- Entrepreneurs
- Pressure from major employers

Worksheet 2-2 in Appendix B provides a tool for assessing these drivers in a state. Columns are provided for the window of opportunity time frame (if applicable) and for commenting on the potential risk and reward of the driver, which is beneficial to understand, because an Executive Order in one state, for example, may have more force or effect than an Executive Order in another state. Thus, it may not be worth pursuing an Executive Order if it would not carry much weight. There may be more than one driver or catalyst influencing the statewide HIE effort. The more drivers or catalysts present in a state, the more incentive there is for collaboration and sharing of health information. The state should also continue to be alert to identify and take advantage of drivers or catalysts that may arise as the effort progresses.

3. Role of the State-Level HIE Initiative

The role of the state-level HIE initiative should be determined early on and should be based on the state's needs and priorities. The role state government can play must also be explored. Research on market characteristics could help identify these needs and assist in evaluating what services or products are feasible and what resources can be used. Sound business planning is an essential prerequisite to creating a viable organization. One particular market characteristic that greatly affects the role of the state-level HIE initiative is whether the state has local or regional HIE efforts already under way. Other factors, such as the prestige of stakeholders driving the effort, capabilities and availability of the human resources for the effort, ability to access sufficient financial resources, the strength of countervailing influences, and the political momentum that has developed could also determine the direction and role that the state-level HIE initiative assumes. Keep in mind that the role may also change across time and as circumstances dictate.

The overall role of state-level HIE initiatives can be loosely grouped into three broad categories:

1. HIE Enabler/Readiness – focuses on coordinating and enabling ongoing regional HIE initiatives.
2. HIE Outsourcing/Technical Partnership – focuses on the business and policy aspects of HIE, but outsources the technology implementation and services.
3. HIE Operator – focuses on implementation and management of the technical and business operations of HIE.

The purpose of highlighting these three categories is to facilitate the reader's conceptualization of the general roles that a state-level HIE initiative can play. There are no clear dividing lines between these categories, and they are not mutually exclusive. For example, the state-level HIE initiative may do all three by trying to convene and advance local HIE efforts, determining the policies and standards that applies statewide, and also conducting limited operations, such as contracting and interfacing with national health data sources on behalf of the state and then transmitting that data to the local HIE initiatives, as appropriate. Another example would be where a state-level HIE initiative outsources some of the technology applications, but develops and maintains the master patient index and the clinician index. There may be other mixes of roles, such as where a state-level HIE initiative is responsible for training, roll-out, and first-tier help desk, but it outsources the application development, hosting, maintenance and second-tier help desk support.

Tasks

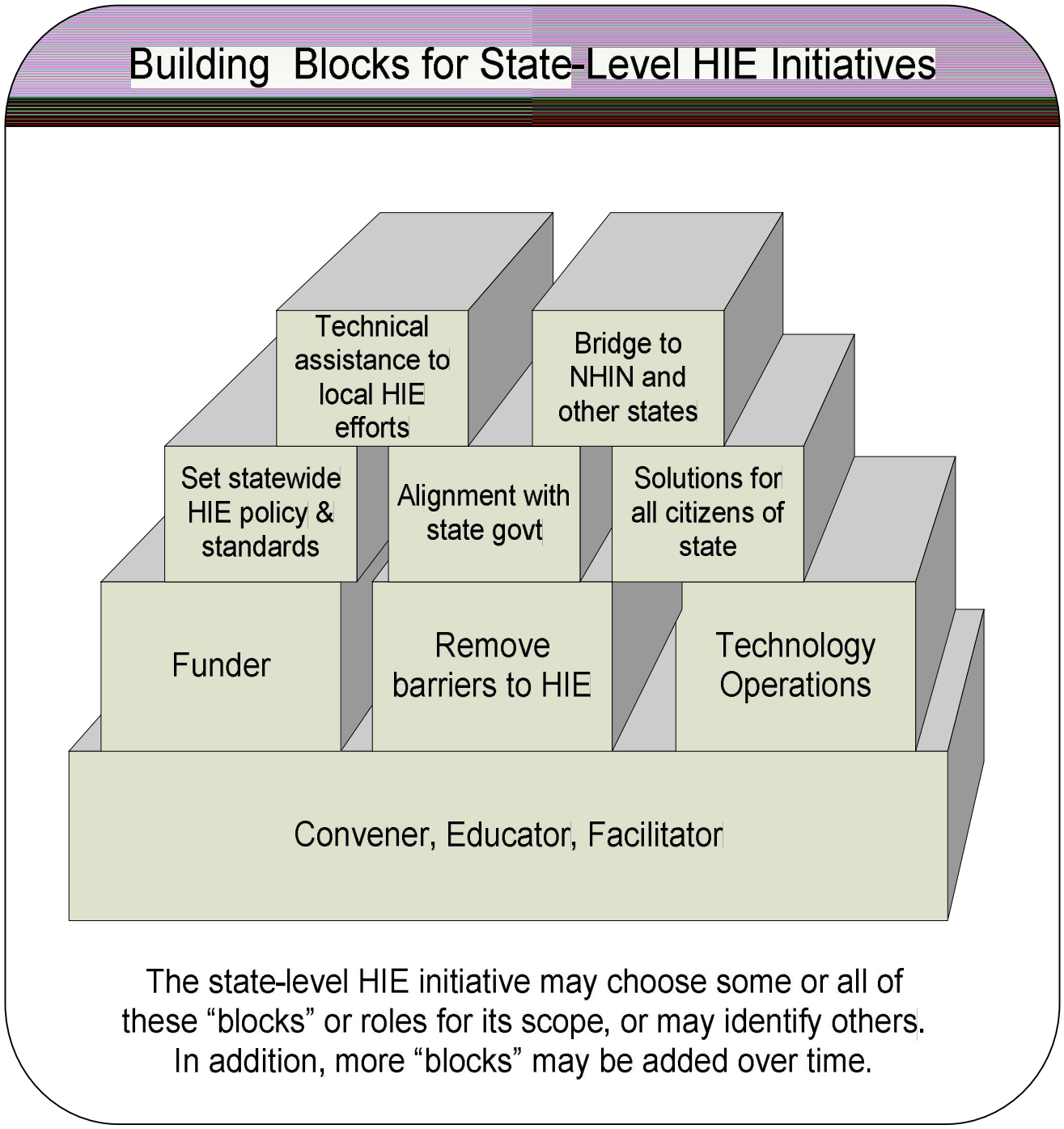
1. Identify possible roles that may be appropriate to the state-level HIE initiative on the basis of its state's market characteristics and other factors. (***Worksheet 3-1 in Appendix B***)
2. Explore the role state government can play in the state-level HIE initiative. (***Worksheet 3-2 in Appendix B***)
3. Prioritize those roles and develop time frames for related work and business planning, as applicable.

Discussion

Role of the State-Level HIE Initiative

Many factors influence health-related organizations, and there are a substantial number of interdependencies between those organizations. Recognizing that there is no "one-size-fits-all" approach is important because of the large number of factors that can influence the development of the state-level HIE initiative. The results of the research and the consensus of the group concluded that there are no particular models per se for state-level HIE initiatives but rather different functions or roles that the state-level HIE initiative could choose to assume. ***Figure 2*** graphically depicts the basic categories of functions or roles that have been identified for state-level HIE initiatives. Although it is up to the particular state to decide which of these building blocks would be most beneficial for its circumstances and long-term goals, the basic function or building block that appears common to all state-level HIE initiatives is that of Convener, Educator, and Facilitator. In addition, as the state-level HIE initiative matures, more building blocks can be added to enhance the organization further and/or to meet changing demands and conditions.

Figure 2.



The following is a brief listing of sample common roles of a state-level HIE initiative by general category. A more detailed description of each of the roles is provided in ***Worksheet 3-1 in Appendix B,*** which serves as a tool to track the importance and feasibility of these roles for a particular state-level HIE initiative. The recommendation on whether the particular role is required or optional is noted in the worksheet. Because state-level HIE initiative development is in its infancy, this listing will likely expand as more possible functions or roles are discovered.

Convene, educate, and innovate:

- Convener of stakeholders
- Education and advocacy (use as bully pulpit or to provide proactive guidance, when needed)
- Track federal policy, proposed legislation, and federal strategic direction and then communicate that with local HIE efforts and work together to review state and local strategic direction in light of the federal direction
- Serve as a source of information about local HIE efforts, if applicable
- Encourage the adoption of HIT and/or EHRs to support the infrastructure capacity for statewide HIE
- Facilitate consumer input, monitor public opinion, and help communicate with the public

Coordinate, develop, and enforce policy, standards, and legislation:

- Promulgate standards to apply to all HIE efforts in the state and/or vendors doing business in the state
- Lead in development of public policy for statewide HIE goals
- Identify statewide barriers to HIE, develop plan to address, advise on legislation or other actions to remove barriers, and identify and remedy gaps in HIE service (e.g., underserved areas)
- Enforcement of HIE policy

Gain efficiencies within state government:

- Help the various state government agencies share their information more effectively and efficiently and avoid making complex internal changes

Connect with communities, neighboring states, and the federal government:

- Neutral forum between local HIE efforts and/or stakeholders to resolve disagreements, but only as they relate to the statewide effort
- Link state (and local HIE efforts, if applicable) to nationwide HIE efforts (e.g., NHIN)

Negotiate, facilitate, and operate:

- Negotiate arrangements with vendors for purchase of products or services for local HIE activities and exercise leverage to facilitate meetings
- Facilitator of funding of local HIE efforts, if any (not necessarily be the source of funding but rather assist and facilitate funding)
- Technically link local HIE efforts together, if applicable
- Provide technology services or other assistance to areas of the state not well served by local HIE efforts, if applicable
- Serve as central hub for statewide or national data sources and shared services
- Provide other administrative support and serve as an information resource to local HIE efforts (e.g., legal support, grant availability, grant writing and administration, technical services, options for technical architecture, list of possible vendors)

Role of State Government in HIE

State government's engagement in the exchange of healthcare information is crucial, but this need is perhaps not widely appreciated. Although such a need is implicit through a wide range of federal efforts and initiatives in specific states, much work remains to be done, state by state, to raise the priority of HIE in the context of the many other pressing priorities within state government.

State government is a stakeholder in several ways: payer, employer, provider, regulator, public health (State Department of Health). Many departments and agencies have an interest and/or may wish to be involved. In addition to health agencies and public employee benefit plans, governors' offices and agencies dealing with education, aging, mental health, corrections, insurance and state CIO's office may have important interests. Legislative research agencies and individual legislators may also have a stake in the success of HIE. Thus, what role the state government plays in the state-level HIE initiative can vary. ***Worksheet 3-2 in Appendix B*** details possible roles that state government can serve to benefit the state-level HIE initiative and provides a tool for tracking feasibility.

Opportunities and imperative for the state-level HIE initiative

One imperative for state-level HIE initiatives stems from states' role as purchasers. States finance specific healthcare for a number of groups, including Medicaid recipients, state employees, and sometimes the uninsured. Through Medicaid and employee benefit programs, state government (with federal Medicaid support) is often the largest payer in a state. Using their market power, state governments can foster a uniform approach to negotiating with interstate or national organizations (e.g., health plans, sources of prescription data, sources of clinical laboratory information) in conjunction with or on behalf of communities and organizations within the state.

States' responsibility for healthcare goes beyond financing individual care. In their roles as purchasers and providers, states have opportunities and imperatives to improve the value of healthcare, and they seek the information necessary to do that. Alone or in partnership with the federal government and communities, states play an important role in ensuring the availability and quality of healthcare for a number of different groups and in a variety of settings:

- Medicaid recipients
- Persons with disabilities
- The elderly
- Children
- Underserved communities
- Critical access
- Community clinics
- Public health

Public goods and social goods

States provide the frameworks within which markets can operate and provide social goods—things that society values for non-monetary reasons and that have a greater benefit for residents than the market can convert to profit, such as fairness and social coherence. They also provide public goods—things that cannot be broken up into commercial fragments without diminishing their value and that cannot be provided exclusively to individuals. Public health activities such as communicable disease surveillance and immunization are classic examples. As is the case with public infrastructure, law enforcement, education, and a broad range of other social goods, states invest in the long-term health of all their citizens through both social goods, such as health-related services, and broader commercial and public good roles, such as information collection. As treatment options expand, costs escalate, and the care paradigm shifts increasingly from acute care to prevention and long-term care, the benefits of care fall out of sync with the costs. States are arguably in a unique position to improve healthcare as its citizens migrate among delivery sites and payment structures.

Creating infrastructures and supporting development in the health sector

Governments typically support infrastructures and fund research and development as public goods. Much as they do when developing an economic climate for industry, states have an opportunity to intervene when markets fail to develop in directions that promise long-term benefits for all, either by supporting initial investments or by creating ongoing funding streams. States can improve the financial sustainability of infrastructures that support the exchange of clinical and administrative information required to deliver healthcare services. Activities can be directed at regional coalitions, individual care providers, hospitals, or other healthcare delivery organizations. Some options include:

- Tax incentives
- Bond financing
- Conditions for ongoing state financial support to specific healthcare activities (e.g., payments to hospitals, nursing homes, pharmacists, physicians)
- Pilot projects for healthcare delivery, technology development, research, or other critical activities
- Coordination of healthcare infrastructure with the broader industrial agenda within a state

Regulatory and legislative roles

States regulate the health sector in a number of ways: through broad policy setting, licensure, implementation and enforcement of regulations, and incentives tied to financing. These roles offer a number of opportunities for promoting public objectives related to HIE statewide. Among the examples are:

- Licensing of healthcare professionals
- Regulation of healthcare services
- Healthcare confidentiality and consumer protection laws
- Health insurance law and regulation
- Legal and regulatory expertise and support for those who interpret regulations
- Setting and enforcing or incentivizing common technical and policy standards

The vital link between communities and the federal government

A key imperative for state-level HIE initiatives stems from their location in the intergovernmental system—between the federal government and local communities. They have a unique role in representing all their residents in interactions across their communities, with their neighboring states, and to the federal government. Roles include:

- Setting standards of practice, financing, and technology across communities within a state
- Coordination of efforts across state borders (e.g., a local healthcare market could span multiple, contiguous states)
- Being the eyes and ears for the federal government with respect to surveillance within the state (e.g., Medicare and Medicaid fraud, clinical misbehavior)

A note on public health

Because of its public health function and its relationship to county and local health departments, the state's Department of Health (or its equivalent) is in a unique position to be able to facilitate and possibly spur appropriate health data sharing between providers (and other sources of data) with public health departments for the purpose of biosurveillance to detect, monitor and/or manage bioterrorism events, disease outbreaks, and pandemics. In addition, public health departments that already collect certain information, such as immunizations, should consider ways to share this information with providers to improve care. The HIE infrastructure may also be used as a conduit to transmit or relay vital information to local providers. Having public health engaged from the beginning of the state-level HIE initiative development will benefit all involved. Supporting these public health needs should also be considered in formulating the financial model.

4. Governance

Several aspects related to governance and structure of the state-level HIE initiative should be addressed at the outset. They include considerations regarding: (a) source of authority or power, (b) choice of legal entity, (c) governing structure (e.g., Board, decision-making group), and (d) approach to transparency. Note that an informal Steering Committee or group may be all that is necessary until the state-level HIE initiative matures (or it may be decided that an informal group is all that is necessary if that is the consensus on the best approach for the particular state).

Tasks

1. Identify the critical stakeholders. (***Worksheet 2-1 in Appendix B***)
2. Consider what activities can be undertaken before formation of the legal entity and establishment of formal governance structure.
3. Understand the source of authority for the state-level HIE initiative.
4. Review and consider the guiding principles from this project regarding choice of legal entity. (***Worksheet 4-1 in Appendix B***)
5. Determine the choice of legal entity on the basis of the planned activities, services, and products and role of the state-level HIE initiative. (***Worksheet 4-2 in Appendix B***)
6. Review and consider the guiding principles from this project regarding governance structure. (***Worksheet 4-3 in Appendix B***)

7. Create the governing structure (e.g., Board, council, management committee) that represents critical stakeholders. (***Worksheet 2-1 in Appendix B***)
8. Review and consider the guiding principles from this project regarding transparency. (***Worksheet 4-4 in Appendix B***)
9. Consider what approach to use for transparency. (***Worksheet 4-5 in Appendix B***)

Discussion

Pre-formation Activities

There may be many activities that precede the actual formation of a governing body for the state-level HIE initiative. Several efforts have embarked first on a proof-of-concept exercise or launched pilot projects to test the feasibility of a particular planned activity, service, or product. Other state-level HIE initiatives have used surveys to gather information about needs and positions of the various stakeholders in the state. Some state-level HIE initiatives have held regional meetings with stakeholders or open public meetings to gather information and to begin the collaborative process to bring stakeholders together to discuss HIE.

In addition to a governing body, discussed later in this section, several state-level HIE initiatives have also used committees and workgroups to address specific tasks or topics. Many of these workgroups were formed prior to the official governing body being established. Examples include committees for making recommendations on certain product functionality or service offering (e.g., providers affected by a clinical messaging product), clinical (to recommend what new services or products would be of most benefit to treatment of patients), technology architecture, standards, financial, governance, and legal or policy. It is imperative that activities of the various committees be communicated and coordinated to ensure alignment of all efforts with the state-level HIE initiative vision and goals.

The states studied in this project varied greatly in the origins of the state-level HIE initiative, including the following: established by state legislative mandate, governor-appointed advisory council, using pre-existing entities or forming a subsidiary to a pre-existing entity, and grassroots efforts by providers. How to decide who will be on the governing body will be influenced by the origins of the state-level HIE initiative and also by the building blocks discussed in the "Role of the State-Level HIE Initiative" section (see also ***Figure 2***). In particular, there may be a different composition of the governing body required if the state-level HIE initiative will be conducting technology operations.

The time it takes to decide on the governance structure of the state-level HIE initiative varied widely among the states studied. Some have taken as long as two years, whereas others have taken only a few weeks. In addition, the state-level HIE initiatives have also been diverse in the timing of when the governing body is established. Some have established their governing body before initiating any other activities, whereas others have formulated their governance as other activities (such as technology operations planning) were going on concurrently.

Source of Authority or Power

In launching a state-level HIE initiative, careful consideration should be given to the source of authority for the new entity or initiative. Here are some examples:[12]

[12] For a recent analysis of state-level activity related to health information technology and exchange, see "Health Information Exchange Projects: What Hospitals and Health Systems Need to Know," prepared by Manatt Health Solutions for American Hospital Association, 2006.

1. The clearest source of authority for a state-level HIE initiative is a state statute that defines the mission, purposes, governance structure, and budget for the new entity. There are many examples of state statutes that create public benefit corporations, and these entities often have governing bodies composed of public and private representatives. A state statute can also confer on the new entity specific powers relating to defining a state plan for HIE, development of health information standards, funding parameters for local or regional projects, and other matters germane to developing a statewide health information infrastructure.
2. Executive Orders creating an advisory body to the governor.
3. Sole source contracts providing an independent entity with funding to accomplish specified purposes consistent with advancing state interests.
4. Memorandums of understanding defining collaboration with state agencies.
5. State officials with voting power serving on the Board of nonprofit organizations.
6. State officials serving on the Board of nonprofit organizations in an ex officio capacity.
7. In some cases, state-level HIE initiatives have been started by private stakeholders, often with charitable or business objectives, and have no official relationship to the state. In such instances, the source of authority of the state-level HIE initiative comes from the community's acceptance of its role. Such acceptance often results from a variety of factors, including the mission of the organization, the independence and diversity of the organization's Board of Directors, and the ability of the organization to provide knowledge and leadership with respect to a defined set of issues, and the success of the effort.

As the field matures, more sophisticated public-private vehicles for advancing state policy objectives will likely emerge.

Note that using the state as the source of authority may not be advantageous in all circumstances. A state-mandated organization may be viewed negatively, or as not neutral, and may vest too much control in state government. However, absent any state authority or collaboration, an organization may have difficulty getting traction. A balanced public-private partnership is recommended, and only one that brings value to all stakeholders will endure.

Choice of Legal Entity

Forming a state-level HIE initiative does not necessarily require that a new legal entity be formed. A pre-existing entity could be used, as long as the objectives of the state-level HIE initiative fit within the pre-existing entity's corporate purposes and any changes necessary to the bylaws or other governing documents were effectuated.

Another option is to form a virtual state-level HIE initiative through the use of contracts and memorandums of understanding to establish the relationships between the parties or stakeholders and the governing structure for decision making.[13]

If a new organization were to be formed, the consensus from the research project on the choice of legal entity for a state-level HIE initiative resulted in the following principles:

[13] For an example of the multiparty data-sharing agreement and governance structure for a virtual HIE organization, see Christopher S. Sears, Victoria M. Prescott, Clement J. McDonald, "The Indiana Network for Patient Care: A Case Study of a Successful Healthcare Data Sharing Agreement," *American Bar Association Health eSource*, September 2005 (also at http://www.regenstrief.org/medinformatics/inpc/INPC_Paper).

PRINCIPLES FOR CHOICE OF LEGAL ENTITY

1. **If the state-level HIE initiative decides to form a legal entity, a not-for-profit corporation is recommended.** The state-level HIE initiative may begin as collaborative with little formal structure, but greater formality will be required as its functions and scope of operations and influence grows. Because the organization must secure support from the public sector and from other nonprofits and will most likely need to secure funding through grants, the not-for-profit form will be most advantageous. The specific tax exemption of the nonprofit corporation should be decided with the advice of legal or tax counsel. A full understanding of the implications of nonprofit status (e.g., requirements for financial disclosures, restrictions on certain activities) should also be explored with legal and tax counsel.
2. **To the extent feasible, consider the future vision for the organization when deciding on entity form.** Designing the entity is a deliberative process and discussion should begin early. The corporate form may evolve across time as roles and functions adapt; for example, a nonprofit may form a for-profit subsidiary for some purposes.
3. **It is not advisable for the state-level HIE initiative to be a state agency, but creating an entity by statute, or otherwise as a result of state action, is acceptable, as long as the governance is balanced public-private governance (that is, not weighted heavily toward government).** Ensuring balanced public-private governance will aid in encouraging stakeholder buy-in and establishing an entity that can be responsive.

Samples of the types of legal entities that may be possible are:

- Not-for-profit 501(c)(3) charitable organization
- Not-for-profit 501(c)(4) social welfare organization
- Not-for-profit 501(c)(6) mutual benefit organization
- Virtual HIE that is linked contractually but with no separate new entity
- Quasigovernmental entity
- State agency
- Partnership or limited liability corporation (LLC) pass-through entity
- Special joint powers authority
- Cooperative

Worksheet 4-2 in Appendix B provides a tool to assess the array of options to consider with legal counsel's advice regarding advantages and disadvantages and what is permitted under the state's corporation laws when choosing the legal entity for the state level HIE initiative. Thought might also be given to the creation of subsidiaries or other affiliated organizations to perform specific functions (e.g., a particular technology service offered by the state-level HIE initiative) and/or to shield the state-level HIE initiative from potential liability resulting from particular activities so the whole organization is not jeopardized by some limited actions or omissions. Tax implications may also arise that would necessitate creating a subsidiary.

Governing Structure

The consensus from the research project resulted in the following principles regarding the governance structure of the governing body of the state-level HIE initiative. They are also listed in ***Worksheet 4-3 in Appendix B*** in the form of a tool for considering issues in one's state. For the

purposes of this project, "governing body" shall refer to any body with governing authority (e.g., advisory council, executive committee, Board of Directors).

PRINCIPLES FOR GOVERNING BODY COMPOSITION AND STRUCTURE

Selection and Representation

1. **Governance of the state-level HIE initiative is critical to the effectiveness of the organization.** Careful thought and effort should be taken to ensure that the governance structure reflects the balanced interests of the key stakeholders. However, it was noted that those who are financially supporting the HIE effort may demand greater representation on the governing body.
2. **Senior leadership on the governing body is necessary for the state-level HIE initiative to accomplish its goals.** "C-suite" directors will have experience in governing and be able to make decisions that commit their organizations (e.g., financial and resource commitments). The governing body is responsible for setting strategy, securing funding, and exercising oversight of all operational work. The participation of these senior-level representatives is necessary to convey the high-level status of the governing body and to gain the highest level of experience and expertise.
3. **Governing body composition should be sized to get work done and include all critical stakeholder interests; mechanisms for participation should be designed to engage those who may not have a seat**. Stakeholders must have a mechanism for meaningful participation, but, at the same time, the governing body must be sized to be workable. Workgroups and subcommittees are common ways to include non-governing members in the work of the organization.
4. **Governing body composition must have balanced stakeholder representation.** Be careful not to be held hostage by financial supporters. For states with multiple local HIE efforts, consider including the local HIE leaders on the governing body.
5. **Appointments should be made by the governing body on the basis of the needs of the organization. Stakeholder organizations may nominate qualified representatives but should not have the authority to appoint their own representatives or pass on a seat**. The governing body should make appointments on the basis of the skills and competencies needed to carry out the work. Organizations should not own seats or designate their own representatives without explicit action by the governing body.

Governance Conduct

6. **Rules of engagement for stakeholders must be set early and administered consistently**. A tone of collaboration must be set, and governing body members should, to the extent possible, leave their own proprietary agendas at the door to encourage the growth of the larger cooperative effort.
7. **The formative governing body must commit to putting in the time and staying in place until the formative work is done**. Stringent rules for minimum required participation are needed, particularly in the early period. A clear understanding of expected duties by the governing members at the outset is important because early turnover could compromise progress. The role of governing body members will be determined by the building blocks the state-level HIE initiative decides to use.
8. **The processes for governing body development and selection, as well as participation in other volunteer roles, must be explicit and transparent**. Although formative governing bodies, workgroups, and committees may be composed of those who are championing the

state-level HIE initiative, a transparent mechanism for participation must be put in place early to avoid disenfranchisement of stakeholders.

9. **Bylaws and other establishing documents should be designed to allow reasonable flexibility to the extent permitted by law so the organization may adapt as early lessons are being learned**. Bylaws should contain only minimum language on corporate purposes (e.g., for improvement of clinical care, medical research and education), to the extent possible. Bylaws should address voting rights (e.g., quorum, percentage required for decision) but should not be so restrictive as to inhibit action.
10. **State-level HIE initiative governing bodies must follow all established practices for legal and effective governance**. The behavior of the governing body will make or break the organization. Governing bodies must be scrupulous in ensuring that their members avoid all conflicts and dualities of interest, including the perception of same. They must also engage in practices that continuously improve their effectiveness. Allowance should be made for removing governing body members for cause (e.g., failure to carry out their fiduciary obligations as a director, undisclosed conflicts or dualities of interest, or failure to attend meetings).
11. **It is imperative that the governing body members serve the interests of the state-level HIE initiative by thinking above their own organizations' immediate interests and holding to the vision and the long-term goal of healthcare data sharing statewide**. It is common for governing body members to have some inherent interest in the state-level HIE initiative's activities because they are often stakeholders. In particular, if vendors or other organizations providing services to the state-level HIE initiative are voting members of the governing body, direct contractual relationships with such organizations should be carefully monitored and scrutinized to ensure a fair and equitable arrangement for all parties is concluded.
12. **The needs of the organization will likely change over time and the governing body may need to undergo a transition to remain effective**. The state-level HIE initiative will evolve in response to market, technology, political, financial, and other factors. Having a periodic (e.g., annual) review and evaluation plan for assessing the governing body effectiveness is recommended. Term limits, staggered terms, and other mechanisms for review and change in members should also be considered.

Staff and Legal Counsel

13. **Legal counsel to the entity should participate in meetings of the governing body but not serve as a director**. Having the organization's attorney attend the governing body meetings helps ensure legal guidance early and throughout the process. The state-level HIE initiative may be composed of competing entities; thus, one crucial governance issue is how to deal with antitrust issues.
14. **Role of state-level HIE initiative staff in good governance is also an important component to success**. State-level HIE initiative staff should: (a) plan meaningful work to engage the governing body, (b) continually communicate the value of being on the governing body, and (c) educate governing body members one-on-one, when possible, to ensure all are on the same level of understanding on a topic.

State Government

15. **Appropriate involvement in governance from state government representatives is necessary, but governance should not be controlled by a state agency**. Government representatives should not have majority say or exert undue influence because this may run counter to the need for strong private sector leadership.

16. **Elected government officials should serve only if their political tenure and status will not compromise the long-term focus of the organization. Similarly, individuals appointed to the governing body by the governor, or through other governmental process, should be committed to follow the organization's vision**. States vary in government structure and in whether some positions are elected, appointed, or hired. Due consideration should be given to the potential effect on the state-level HIE initiative. A plan should be in place for weathering changes in political leadership.

Worksheet 2-1 in Appendix B can be used as a tool for cataloguing and tracking the desirability of having particular stakeholders represented on the governing body. Keep in mind that which stakeholders are critical will depend on the role and the planned activities, services, and products of the state-level HIE initiative. Note that the different roles may require different skill sets of the persons involved (e.g., a financing role would require different skills than a technology bridge role). ***Table 1 in Appendix C*** gives an overview of the governance composition of the nine state-level HIE initiatives included in this research as of the date of this report.

Approach to Transparency

The consensus from the research project resulted in the following principles regarding transparency:

PRINCIPLES FOR TRANSPARENCY OF STATE-LEVEL HIE INITIATIVE ACTIONS

1. **Transparency is important, but practices will vary depending on the role and the stage of development of the state-level HIE initiative.** Practices range from full open meetings with all activities publicly disclosed to private meetings with minutes and other activities fully or partially disclosed to the general public (e.g., confidential financial or procurement information withheld) to private meetings with limited or no information available to the general public but openness and transparency between stakeholders.
2. **Open records law trumps, if applicable**. A state-level HIE initiative may be subject to state open records law if it is organized in a certain manner (e.g., more than 50 percent of entity's revenue comes from state grants or contracts).
3. **Even in the absence of law, full transparency with the critical stakeholders is desirable to gain broad stakeholder support and engagement**. Successful state-level HIE initiatives operate for the public good and have an inherent obligation for accountability.

Transparency is viewed as important to the success of the state-level HIE initiative. Transparent to whom is more difficult to specify. The states sampled in this project cover almost the entire spectrum of transparency. ***Worksheet 4-5 in Appendix B*** presents the continuum of transparency in the form of a tool to enable evaluation of options for one's state. In addition, the state-level HIE initiative may have certain public meetings, apart from governing body meetings, to obtain public input.

5. Initial Funding and Financial Models for Sustainability

To date, many state-level HIE initiatives, as well as local HIE efforts, have received start-up funding. There are multiple sources of this start-up funding, including federal grants, state grants, private foundation grants, and contributions from regional stakeholders who support the mission, goals, and objectives of HIE projects. This initial funding is typically used for activities such as convening and educating stakeholders around a common framework for pursuing an HIE project, forming a new entity (if necessary) to pursue the project, putting in place a governance structure for making decisions about the project, and developing a business plan for the long-term funding and sustainability of the project.

It is fairly common for HIE efforts to receive some initial funding. However, there does not exist today any magic bullet with respect to the options or strategies to achieve long-term financing of these sorts of projects. In fact, many involved with HIE efforts consider the issue of longer term sustainable financing to be one of the major barriers to HIE initiatives going forward.

While reviewing the recommended tasks, it is useful to keep in mind some of the key building blocks discussed earlier (depicted in ***Figure 2***). The definition of the scope and functions of a state-level HIE initiative effort will significantly influence the strategies for obtaining long-term sustainable financing. In particular, the "Convener, Educator, Facilitator," "Funder," and the "Technology Operations" building blocks will come into play in the discussion.

Tasks

1. Review and consider the guiding principles from this project regarding initial funding. (***Worksheet 5-1 in Appendix B***)
2. Review and evaluate potential sources of initial funding, including assessing the effort required and possible restrictions (risk) and the potential funding amount (reward). (***Worksheet 5-2 in Appendix B***)
3. Review and consider the guiding principles from this project regarding financial sustainability models. (***Worksheet 5-3 in Appendix B***)
4. Examine a variety of financing models to determine the one most appropriate and feasible, given the state's market characteristics, vision or mission, planned activities (and building blocks), and stakeholders' input.
5. Determine whether the state-level HIE initiative will be conducting technology operations (e.g., actually hosting and sharing healthcare data):
    a. If the state-level HIE initiative is planning to conduct technology operations, consider and assess feasibility of different services for generating revenue. (***Worksheet 5-4 in Appendix B***)
    b. If the state-level HIE initiative is NOT planning to conduct technology operations, consider and assess the potential sources of revenue for services. (***Worksheet 5-5 in Appendix B***)
6. If possible, conduct a proof-of–concept exercise for new services or products with some of the stakeholders that will be involved to evaluate the financial feasibility of pursuing the activity.
7. Develop a business plan to achieve short- and long-term goals. Comprehensive, sound business planning is crucial to the viability of the state-level HIE initiative. Although no worksheet or in-depth explanation of business planning is included in this workbook, those

leading the state-level HIE initiative are expected to use generally accepted business practices for thorough business planning.

Discussion

Initial Funding

The consensus from the research project on the initial funding for a state-level HIE initiative resulted in the following guiding principles (See also ***Worksheet 5-1 in Appendix B*** for a tool to assess each principle as it applies to one's state):

PRINCIPLES FOR INITIAL FUNDING

1. **Understand the goals of each stakeholder and the benefit that they perceive the state-level HIE initiative is capable of providing.** Managing and meeting desired benefits is a critical prerequisite to assigning value and securing funding. Foster a collaborative approach to forming the state-level HIE initiative.
2. **On the basis of the goals and model for the state-level entity, determine start-up organizational funding needs and begin to develop viable sustainability options and/or a business plan**. Consider the feasibility for sustainability from the outset because this may lead to a more realistic assessment of the level of start-up funding needed. For example, multiyear commitments may be sought from start-up funding sources.
3. **Engage key stakeholders, such as private payers, in the funding discussions early on**. Recognize that HIE is not stand-alone. Find the role for the state-level HIE initiative within the context of the whole state healthcare model. The state-level HIE initiative must be part of a transformed healthcare system that addresses healthcare inflation, healthcare quality, equity, and the roles of individuals, payers, employers, providers, and intermediaries.
4. **Seek start-up funding from multiple sources to reduce the risk of reliance on one source and to secure as much seed funding as possible**. Examples of initial funding sources include: (1) federal grants, (2) state funds (e.g., matching grant, bond issue, contract, tobacco settlement funds), (3) Blue Cross/Blue Shield insurance demutualization funds, (4) foundation grants, (5) stakeholder contributions, (6) membership fees from stakeholder organizations, (7) prepayment of subscription or use fees (if applicable), or (8) vendor shares in risk contracts (if applicable). Be sure to understand the practical implications of the state-level HIE initiative's legal entity status and consult with legal counsel on funding opportunities and/or restrictions.
5. **Seek in-kind services to reduce initial expenses**. Stakeholders could be solicited for assistance in underwriting legal start-up costs; providing expertise, staffing and administrative support, office space, hardware, and networking connectivity (if applicable); and/or HIE infrastructure.
6. **Seek direct financial support from the state. In addition, secure visible forms of endorsement of the state-level HIE initiative and the importance of its work**. The state-level HIE initiative serves a public good, and the state should contribute to start-up financial support. In addition, forms of endorsement can help the state-level HIE initiative with fundraising from other sources. States do not benefit from competing initiatives at the state level.
7. **Ensure alignment of grant or contract requirements with the state-level HIE initiative's objectives and vision**. Avoid seeking grants that require activities or consume resources for projects that are not priorities for the organization or that create a challenge for core participants. Also, be cognizant of any strings (restrictions on use of funds, matching

fund requirements, etc.) and carefully consider their effect on the organization before deciding to apply for the grant.

The state-level HIE initiative needs to decide how much funding is necessary to accomplish its start-up and short-term goals. Once that is determined, ***Worksheet 5-2 in Appendix B*** can be used for gathering and assessing information regarding a variety of potential initial funding sources.

The consensus of those involved with this research project is that the most important purposes of initial funding of a state-level HIE initiative are fourfold:

(1) To build a strong consensus among multiple stakeholders with respect to the purpose and functions of the state-level initiative;
(2) To define the role of state government in assisting the state-level HIE initiative;
(3) To put in place a decision-making structure; and
(4) To develop a detailed, comprehensive business plan for the state-level HIE initiative, which includes defining the capital and operating expenses of the project and the sources of revenue for the project.

The initial funding could also be used for actually building some of the technology architecture, if the state-level HIE initiative will be conducting such work (the "Technology Operations" building block); however, this should be balanced with the need to ensure a viable structure and plan for the state-level HIE initiative at the outset.

Financial Models for Sustainability

The financial sustainability model for state-level HIE initiatives (and maybe all HIE initiatives) is perhaps the most difficult challenge. Because market characteristics continue to change across time, continuing to evolve the financial sustainability model will always be important. In developing a plan to address the long-term financial sustainability of a state-level HIE initiative, consider the following:

1. There is no magic bullet for developing a long-term financial plan for a state-level HIE initiative. Most of the projects involved in this research are still at relatively early stages of developing their long-term financial plans; however, a small number of state-level HIE initiatives in this study achieved financial sustainability for certain HIE services or products. That said, a review of the project plans for these and other projects, as well as the emerging literature on the financing of HIE efforts, provides some useful guideposts for those considering a state-level HIE initiative.

2. It is important for the state-level HIE initiative to determine thoughtfully what activities and functions it plans to perform - what we are calling the building blocks (depicted in ***Figure 2***). Which building blocks are used for the state-level HIE initiative will determine the range of options for financial models and sustainability long term. Some building blocks or functions may be able to generate revenue, whereas others may not.

3. The level and type of financing that state government is willing to provide to a state-level HIE initiative will have a significant effect on the long-term financing plan. To date, states have moved forward with, or are considering, different approaches to financing HIE efforts. Some states are providing significant direct grant support to local HIE efforts, whereas others are considering creating a capital loan program to support local HIE efforts. In each

situation, a state-level HIE initiative needs to determine how its own activities will dovetail with the state's agenda and how funding made available through the state will support those activities.

4. Because of the nascence of state-level HIE initiatives and the differences in market characteristics among states, there is no *one* recommended model for funding and sustainability. However, some examples of funding and potential sustainability models identified and discussed during this research project are listed here. Note that in addition to these funding sources, the state-level HIE initiative may also receive grants or enter into contracts for certain activities that would generate additional revenue. Therefore, the examples listed refer to how the majority of the earned revenue (as opposed to grants) for the state-level HIE initiative would be generated.
    - **Membership Fee Model**—Stakeholders pay to support shared services for all. Membership fees could be equal for all participants or tiered on the basis of some factor, such as size or use. This Membership Fee Model requires careful consideration of how to set up the participation on the basis of the relative value each participant expects to receive from the shared enterprise. In addition, getting a commitment from a critical mass of members is essential to the financial success of this model.
    - **HIE Transaction Fee Model**—The state-level HIE initiative charges transaction fees for its HIE services or products on the basis of benefit to the participants. Examples include:
        - Transactional fee of $X per clinical result delivered
        - Transactional fee of $X per covered life per month
        - $X per hour for technical assistance
        - $X per month for a license to use a particular software package with the Web

      Unlike the Membership Fee Model, in which participants sign on up front to participate, the HIE Transaction Fee Model requires investment capital or grants to build an infrastructure for the business.
    - **Program and Service Fee Model**—This model involves charging stakeholders for participation in, or outcomes from participation in, program-related activities undertaken by the state-level HIE initiative. For example, fees could be charged for creation and implementation of group purchasing arrangements.
    - **Combination of Models**—One single model may not cover long-term expenses; therefore, it may be beneficial to use a combination of financial models. Many combinations of the models described may be viable for a state-level HIE initiative. For example, a Membership Fee Model could supply some small core funding on a steady basis, and the Transaction Fee Model could be used to supplement at the same time. Some models may not yet be feasible for the state-level HIE initiative, depending on its stage of development. For example, a state-level HIE initiative just forming may not have services capable of generating HIE transaction fees sufficient to cover its costs.

5. Framing the funding for state-level HIE initiatives around phases may be helpful:
    - **Infrastructure Development**—enabling infrastructure of the organization (staff, resources, and, if conducting HIE operations, the basic hardware, operating system, and database software and general architecture for the planned operations), business planning, and establishing the basic policy framework.

- **Capacity Building**—the next level of development to be able to begin receiving and sharing healthcare data, which could include, for example, building the master patient index, the clinician master index, and the interfaces to the data source systems
- **Quality Improvement**—this level cannot be achieved until the first two levels are at a critical mass and requires having enough data available to the state-level HIE initiative to use for quality improvement, research, aggregate reporting, and so on

In considering the strategies for developing long-term sustainable business plans for state-level HIE initiatives, those involved in this research project developed a set of guiding principles that they believe are important to consider:

PRINCIPLES FOR FINANCIAL SUSTAINABILITY MODELS

Technical Operations and Functions

1. **What functions and/or services or products the state-level HIE initiative will provide will be dependent on and determined by market characteristics**. The state-level HIE initiative must ascertain what services will be saleable, generate revenue in its market, and create value. Proof-of-concept analysis and pilot projects can help reduce risks in deciding whether to roll out a new product or service. Seeking prepayment of fees from customers will also give an indication of the financial viability of the new product or service. Market characteristics can change across time, so careful monitoring will ensure continued viability of the particular service.
2. **It is better to begin with limited fundamental functions or services for early results and phase in more complex functions incrementally across time**. Demonstrate value early through services that help build the long-term value case. Start out with a basic function of exchanging health information—perhaps even limited to specific types of data (e.g., only medication history) or specific care settings (e.g., only emergency rooms or inpatient treatment). Target high-value data elements to start.
3. **Long-term funding or sustainability will evolve as HIE functions come online**. Funding levels and mechanisms change with added roles or services and increased efficiency. More HIE services may be able to be added as the clinical record becomes more complete and the data set more rich.
4. **Business plans and a clear value model should be developed for each HIE function. These plans must be flexible and will evolve as the NHIN develops and other market factors change**. Services that do not provide value will be discarded early by taking this approach. The HIE functions capable of being a sustainable revenue source can be more easily identified and targeted. Consider where the market need is and what services stakeholders could benefit from most. One value to stakeholders could be the convenience of only having to communicate and contract with a single entity, the state-level HIE initiative. Long-term financial sustainability will be achieved only when the state-level HIE initiative succeeds in providing true value to its stakeholders and becomes an indispensable component of the HIE fabric.

Stakeholder Engagement

5. **Stakeholders who benefit from state-level HIE initiative services should participate in its funding on the basis of an explicit value model**. The value proposition for elements of HIT must be determined in order to align financial responsibility with the benefit received.

6. **Provision must be made for supporting the needs of stakeholders who must be engaged or served but who lack the resources to contribute financially**. Allocation of the costs associated with the underserved and/or other stakeholders that are not able to contribute monetarily should be considered when designing the financial model.
7. **The most effective way to keep stakeholders engaged is for them to have a financial stake in the state-level HIE initiative and/or for the state-level HIE initiative's services to be indispensable to the stakeholder**. Carefully balancing the financial support required with the perceived value and benefit received by the stakeholder is a difficult task. This balance should be reassessed periodically to ensure it remains equitable. Keep in mind that certain stakeholders may be more willing to participate if other types of stakeholders are at the table. The converse may also be true.
8. **Consider early on how to involve payers in the revenue model**. The number of payers, their market share, type of payer, and the proportion of ERISA plans versus self-funded plans all drive what would be feasible for the state-level HIE initiative. Having a solid understanding of the payer environment and targeting how to leverage and involve payers is critical to the long-term viability of the initiative.

State and Federal Government

9. **Strategize on the feasibility of using state and/or federal funding and fully understand the role and obligations for state and federal funding for HIE at the state and local levels**. This relationship is important to understand to avoid any unintended consequences that could affect the local HIE efforts and/or the state-level HIE initiative's plans. For example, the scope of the rights in and to the data and systems may vary because some grants affect intellectual property ownership and rights. Carefully consider whether there will be a competitive edge if a grant is obtained versus the development being funded by the stakeholders.
10. **The state-level HIE initiative should consider leveraging federal funding to create its state HIE infrastructure, to handle inquiries from other states and to tie in to the federal NHIN, when developed**. In particular, the infrastructure to support public health purposes could be funded with federal grants. However, as noted, it is still important to consider carefully the requirements of any grant and assess its potential effect. In addition, federal reimbursement incentives could be used to help build the HIE infrastructure.
11. **The state government and the state-level HIE initiative should mutually agree how to bridge their architecture (e.g., Medicaid, public health services, etc.) with the state-level HIE architecture. In addition, the state government may create and/or financially support some of the statewide HIE infrastructure so HIE services can occur**. The state-level HIE initiative and state government working together to collaborate on the development of the infrastructure for statewide HIE and/or capitalizing on state government systems or infrastructure (to the extent feasible and appropriate for the long-term vision) may reduce the overall cost. Certain federal incentives to states for use of HIT (e.g., higher Medicaid reimbursement rates for HIE and waivers allowing the use of Medicaid funds for HIE) can help reduce expenses.
12. **Be mindful of proposed state and federal policy or legislation that could affect financial models**. Developments around reimbursement policies and incentives may present opportunities to be considered in the financial plan. It is essential that the state-level HIE initiative carefully track and understand the federal agenda so that it will not invest in an effort that may not be eventually feasible or consistent with the federal direction. On the other hand, waiting for federal action before proceeding with state activities may delay HIE

progress. Consider using national fiscal intermediaries in supporting the state and leverage these connections as the federal agenda evolves.

Other Sources of Funding and Revenue

13. **Seek in-kind or discounted services to reduce ongoing expenses**. Also a principle under the initial funding section, obtaining continuing long-term commitment for in-kind or discounted services will benefit the financial model. If appropriate, consider requiring certain minimum service levels and entering into a contract to document the arrangement, with advice of counsel.
14. **Identify risks and rewards of various sources of revenue**. Inventory and monitor disruptive technologies or business competitors that could overturn your sustainability.
15. **The state-level HIE initiative must balance its need for financial sustainability with local HIE efforts to ensure that its activities complement, rather than compete with or undermine, the financial models of the local HIE efforts, to the extent possible. The state-level HIE initiative should also allow the local HIE efforts to leverage their existing investments and infrastructure to the greatest extent possible**. Careful thought around potential overlap with local HIE efforts allows the state-level HIE initiative to establish the funding stream needed for operations and services, while not supplanting the regional or local HIE activities. The state-level HIE initiative should work collaboratively with the local efforts to assist them in removing barriers to HIE and in scaling up and expanding the local efforts.
16. **Grants may supplement but are unlikely to be a viable source for ongoing funding**. Grants are useful for testing new ideas or for seed funding; however, care must taken to ensure that a sustainable revenue stream is developed to support the effort. That is, avoid seeking a grant to develop a new service that no one would be willing to pay for. This situation can be avoided by getting a commitment up front from the targeted stakeholders who will eventually be paying for the service. In addition, the focus of the grant should fit into the overall vision for the state-level HIE initiative and not distract it from its long-term goals. Note that grant proposals are different from business plans, and a true business plan is recommended for each new service or product contemplated.

Worksheet 5-4 in Appendix B is a tool for use in summarizing the evaluation of potential revenue-generating services for state-level HIE initiatives that plan to or do have HIE "Technology Operations" building block. Of course, a thorough analysis of each potential service is necessary.

Worksheet 5-5 in Appendix B is a tool for use in evaluating potential revenue-generating services for state-level HIE initiatives that do *not* plan to have their own technology operations for the purpose of HIE, but rather the state-level HIE initiative would serve in the capacity of a convener, educator, or other role or building block that does not involve serving as a provider of technology.

6. HIE Policies

The scope of this project includes some preliminary findings on barriers to statewide HIE. State-level HIE initiatives that will be involved, operationally, in sharing health data would likely need to draft and negotiate a data-sharing agreement with the stakeholders involved in the data exchange. In addition, determination of how the data will be used and accessed will factor into the technology requirements and associated development and maintenance costs, which could affect the financial model.

Tasks

1. Review and consider the guiding principles from this research project regarding HIE policy development. (***Worksheet 6-1 in Appendix B)***
2. Identify barriers to HIE in the state, including both business practices and state or federal law. (***Worksheet 6-2 in Appendix B***)
3. If applicable, negotiate an HIE data-sharing agreement. (***Worksheet 6-3 in Appendix B***)
4. Determine the role the state-level HIE initiative will have in deciding on the data model. (***Worksheet 6-4 in Appendix B***)

Discussion

HIE Policy Development

The consensus from the research project on the guiding principles for a state-level HIE initiative regarding development of its HIE policies is as follows. ***Worksheet 6-1 in Appendix B*** is a tool that lists the principles and columns for assessing their importance in one's state.

PRINCIPLES FOR HIE POLICY DEVELOPMENT

Advocacy, Education, and Collaboration

1. **Creating or fostering a culture of collaboration will reduce barriers to statewide HIE**. The creation of a state-level HIE initiative entity will not necessarily result in or ensure statewide HIE. A critical mass of stakeholders must collaborate to sustain HIE efforts long term. In addition, remember that collaboration can originate from self-interest.
2. **Education early and often will alleviate much fear and uncertainty in sharing healthcare data—specifically, education about what is permitted by privacy law**. There are many misperceptions and misunderstandings about the scope of privacy laws (especially Health Insurance Portability and Accountability Act [HIPAA]) that create fear and hesitancy to participate in HIE. When properly educated, stakeholders understand that HIPAA (and many state laws) allow for fairly generous exchanges of health data for the fundamental purposes of most HIE activities, such as patient treatment. Stakeholders (including consumers) may need to work through concepts together to come to common interpretations and shared understandings of applicable laws and barriers, in addition to formal education on HIE issues.
3. **Seek broad and bipartisan political support. Be aware of political forces and agendas within the state**. Approach both parties to educate and gain support for statewide HIE efforts and to lower barriers to HIE policies. Consider carefully whether to use the governor to announce or lead the charge for support because the governor is by nature aligned with one political party. Seek support from a broad range of interested parties for HIE initiatives,

keeping in mind that roles change within a state government and that state government personnel may leave for the private sector and be in a position to provide support there.

4. **Education early and often about the value and benefits of HIE were noted to be essential**. It is important for the governing body and all HIE participants, including consumers, to have a solid understanding of the benefits of secure HIE.

Legal and State Policy Barriers

5. **State-level HIE initiatives can play an important advisory role to help create legislation or Executive Orders to remove HIE barriers**. Presumably, a state-level HIE initiative will convene the state's greatest champions for HIE and thus will be able to serve as a clearinghouse and facilitator for educating public officials about the advantages of HIE and the necessity of removing barriers. Consider whether state-enabling legislation will give legitimacy to the state-level HIE initiative.
6. **Recognizing that state policy also gets implemented through state contracts, the state-level HIE initiative could assist state government in creating model contracts for the state government to use with other HIE stakeholders**. The role of the state-level HIE initiative as a neutral, multi-stakeholder entity will assist in harmonizing the interests of the varied stakeholders.
7. **Start early to identify barriers to minimize their effect on state-level HIE initiative plans**. Identifying barriers early is critical to prevent major roadblocks after operational plans have already been developed and to avoid reworking those plans.
8. **Engage an attorney early on to help identify legal barriers before planning begins**. Legal considerations should be addressed at the outset before technology and operations are implemented that require legal compliance. For example, state law that places restrictions on sharing certain types of data should be considered and addressed when designing the system. Another example is a state law that requires any entity receiving a certain amount of its funds from state grants to be subject to open records law, which could seriously jeopardize the operations if all patient data are public record.

Technology and Operations

9. **Structure the state-level HIE initiative's activities to be able to adapt when state or other law changes, when market forces exert pressure, and when standards or certification requirements change**. Changes in law and in the market are inevitable, and state-level HIE initiatives must be flexible enough to adjust to accommodate such changes. Recognize inconsistencies between and among state and federal laws and standards. Also, be aware of unusual state and federal contracting cycles. Finally, flexibility is needed to account for differences in states' laws to accommodate interstate populations, especially in border areas.
10. **Ensure that IT and health information professionals and those who understand the practicalities of sharing data are engaged when developing plans for operations or setting standards. Use technical and legal workgroups to reach good solutions and consensus on policies**. Their involvement will help assess the effect of HIE policy choices on IT development and implementation time lines and costs.
11. **Work on HIE policies at the same time as operations and technology are being designed to ensure that the HIE policies are reflected in the resulting design and that the HIE policy is feasible to implement**. Policies, operations, and technology are

interdependent and must be considered simultaneously. Policies should also align with governance principles of the state-level HIE initiative.

12. **Focus first on HIE policies for types and uses of data that are easier to gain consensus on (e.g., for treatment at point of care)**. Tackle secondary uses of the data that may be more controversial or more subject to scrutiny (e.g., research use, quality improvement, healthcare operations) after initial trust among the parties is solidified.
13. **Consider and ensure consistency with national standards, formats, and certifications (such as recognized and widely used code sets).** Failure to create policies consistent with national standards and certifications will discourage stakeholders from participating for fear of not being able to be "certified" and for fear of not being able to share data using common code sets and formats (thus inhibiting efficient HIE).
14. **Privacy practices should comply with state and federal law, take into account stakeholders' respective positions, and reflect the key stakeholders' consensus**. Consider the state-level HIE initiative's planned activities when evaluating alternatives for privacy practices. The development of privacy practices are influenced by various factors, such as culture and attitude toward privacy, stakeholder positions, implications for technology and financial model, and liability risk. For example, a "record locator service" data model may be chosen to reflect stakeholders' concerns over a centralized database. Privacy practices should be driven by the state-level HIE initiative's governance process. Remember that consumers are also stakeholders in HIE policy.
15. **Reevaluate each HIE policy periodically to assess whether the policy is helping or inhibiting achievement of the HIE mission**. Look at whether privacy policies are too restrictive. Evaluate if the policies are allowing the HIE to get populated with enough data to be useful and look at whether the right people are able to get access to the right data to treat patients.

Barriers to Statewide HIE

Creating a state-level HIE initiative does not necessarily result in statewide HIE. The value in creating a culture of collaboration should not be underestimated. ***Worksheet 6-2 in Appendix B*** provides a sample of potential barriers to statewide HIE that were noted during the research project. Keep in mind that some barriers could actually have corresponding special opportunities for solutions.

HIE Agreement for Data Sharing

If the state-level HIE initiative will be engaging directly in sharing health data, then a data-sharing agreement will likely be necessary.[14] ***Worksheet 6-3 in Appendix B*** outlines some key issues that should be considered.

Role in Determining Data Model

Although the viability of a particular data model (also referred to as data architecture) is not within the scope of this research project, it is important to determine the state-level HIE initiative's role in determining the data model. To that end, a basic understanding of possible data models is useful. By way of example, here are some data models that an HIE initiative could use:

[14] See also other examples of data-sharing agreements: "Connecting for Health Common Framework," http://www.connectingforhealth.org/commonframework/index.html, April 6, 2006; Christopher S. Sears, Victoria M. Prescott, Clement J. McDonald, "The Indiana Network for Patient Care: A Case Study of a Successful Healthcare Data Sharing Agreement," *American Bar Association Health eSource*, September 2005 (also at http://www.regenstrief.org/medinformatics/inpc/INPC_Paper).

- Decentralized model (e.g., Record Locator Service) involves no data storage of clinical data but rather storage of patient demographic data and a pointer to indicate where that patient has data.
- Central data storage, but with individual "vaults" (files) of data by data source. For example: Hospital A data would be stored in Hospital A's file and not commingled with Hospital B's file. When the requests for data hit the system, the master patient index would pull the data from the various data source files and create a virtual health record for the patient.
- Single community EMR. For example, the data sources (e.g., hospital labs, pharmacies) transmit their information to one central site, and the data is combined and stored in one single EMR for the community.
- Pure conduit model stores no data at all about the patient. For example, the HIE functions more as a router or switchboard for directing incoming data to the appropriate destination, but does not store patient data in a repository for re-use.
- Data storage model that stores the data by type rather than source. For example, laboratory results from all data sources would be stored in a laboratory file, medication history would be stored in a medication history file, radiology would be stored in a radiology file, and so on.

The models described above are not necessarily mutually exclusive. A state-level HIE initiative could implement a mixture of the above. For example, it could store some data centrally, but query other data sources to supplement its record at the time the information is requested. In addition, once the state-level HIE is more robust and offers multiple services, data storage needs may vary by type of service.

Keep in mind that the data model could be driven not only by policy decisions, but also by what the data sources are willing to agree to, the practicalities from the technology standpoint and the end user standpoint (e.g., response time), and the business model and associated costs (e.g., hosting expense, maintenance). In addition, flexibility should be built in, to the extent possible, to allow for change in circumstances, policies and/or additional services.

The ***Worksheet 6-4 in Appendix B*** serves as a tool for exploring options for the role of the state-level HIE initiative in determining the data model.

7. Operations and Technology

The scope of this project does not include discussing the viability or advantages or disadvantages of different data models because this issue will be addressed in the NHIN process. It is important to note the crucial nature of making decisions regarding operations and technology and their interdependence on other decisions such as HIE policies. For example, a state-level HIE initiative would be unwise to enter into a contract with a software vendor before it had determined which HIE policies would apply because it may require significantly more cost and take longer to implement a system that includes heavy audit and consent tracking. It could also affect the speed of the system or the complexity of using the system.

8. Short- and Long-Term Priorities

It is important to consider all the factors (e.g., market characteristics, stakeholders' wishes) when developing the state-level HIE initiative's short- and long-term priorities. Interdependencies of financial model, operations (if applicable), and HIE policies will also play a part in the formulation of such priorities.

9. Expect Change

Once these topics are discussed and decisions made, revisit assumptions and decisions regularly. Be open to changing and adjusting priorities, and even financial models, as needed. Because of the nascence of the HIE efforts on a larger scale, there are no well-proven, commonly used models to emulate. In addition, a state's market characteristics may make it difficult to replicate one state's model in another state. Federal efforts will continue to advance standards adoption and a common architecture for network services, which will eventually be certified. For this reason, it will be important to monitor the work of the Health IT Standards Board, Certification Commission for HIT, and the Nationwide Health Information Network Consortia to ensure investments at a state level will lead to an interoperable infrastructure over time. The results from other ongoing federally-contracted work, such as the Privacy and Security Solutions Project,[15] will also provide information and guidance for states.

[15] The Privacy and Security Solutions Project refers to the $17.23 million "Privacy and Security Solutions for Interoperable Health Information Exchange" contract awarded by the Agency for Healthcare Research and Quality (AHRQ) to RTI International in September 2005. AHRQ and ONC jointly manage and fund this contract. RTI has subcontracted with 33 states and Puerto Rico under its Health Information Privacy and Security Collaboration (HISPC) initiative. The HISPC subcontractors will assess current enterprise-level privacy and security practices and policies related to health information exchange and identify best practices as well as propose solutions for those that may need changing. They will also produce proposed implementation plans. The work on this project is underway and is targeted for completion in the spring of 2007. See www.rti.org/hispc for more details.

Appendix A—Executive Summaries of the Nine State-Level HIE Initiatives Studied

(in alphabetical order)

Executive Summary for California

Report as of Site Visit on 5-24-06

Market Characteristics

Regions:

- California is the largest state in the country and has an ethnically diverse population.
- Although most people live in cities, 75 percent of California is geographically rural.

Local HIE Activity:

- CalRHIO has identified 15 HIE efforts within California.
- Areas where data are currently being shared include Mendocino County, Marin County, Santa Cruz, and Santa Barbara.

Governance

- CalRHIO is a not-for-profit entity formed in January 2006.
- The Board has 22 members and as many as four ex officio members. The Board meets quarterly, with executive committee meetings as needed.
- The state is represented by two ex officio Board members from the State Department of HHS—the Director of the Department of Managed Care and the Director of MRMIB. Federal government represented by the Director of CMS, Region 9.

Funding and Financial Model

Initial Funding

- More than $4,650,000 from several sources including:
  - Sutter Health, $1,000,000
  - Blue Cross of California Foundation, $1,000,000
  - Kaiser Permanente, $1,000,000
  - Blue Shield of California Foundation, $1,000,000
  - California HealthCare Foundation, $450,000
  - University of California Office of the President, $100,000
  - Cedars-Sinai Health System, $100,000
  - Lumetra, $40,000
  - John Muir/Mt. Diablo Health System, $40,000
  - Lucile Packard, $40,000
  - Blue Shield Foundation of California Foundation, $40,000
- Initial funding methods are not replicable in other states because most of this grant funding was not restrictive and could be used for exploring possibilities for collaboration at a statewide HIE initiative level.
- CalRHIO is currently seeking its second round of funding. These grants may be more tied to specific projects or functions.

Sustainability Model

- CalRHIO underwent a business case analysis from a consultant, which was reviewed by the Clinical and Business and Finance Working Groups. It was developed around the major projects, core functions, and infrastructure. Several ways were suggested that the organization could charge for certain services or use a membership fee for services. These suggestions are being vetted with communities to determine the feasibility of models.

Operations and Technology

- Software: There is no operation of linking software at CalRHIO. CalRHIO issued an RFI for vendors seeking potential solutions for its ED Information Linking project.
- Technical Model: RLS is the model at the state level, but CalRHIO may also be a hub for certain statewide data feeds (for example, CalRHIO would set up the data feed from Quest laboratories for everyone in the state and then send the data to the appropriate local HIE organization as needed).
- Standards: There is an extensive list of recommended standards issued for messaging.
- The Clinical Workgroup defined a minimum clinical data set for HIE at the point of care:
    1. Medications
    2. Allergies
    3. Results
    4. Problem list
    5. Past problems
    6. Immunizations
    7. Preventive care
    8. Chronic care management
- HIE Activities: In the last half of 2006, the focus of CalRHIO is on developing and implementing two or three pilot projects to access vital medical information in EDs to test the standards and HIE technical solutions. It may also test, on a limited scale, a medication management and a PHR pilot project.
- Intellectual Property: There is no requirement to be open source.

HIE Policies

- Privacy: California expects to have more stringent privacy requirements than other states because of the culture and the current state regulations in place.
- Legal Barriers: California has hundreds of laws that conflict and is working to identify specific barriers.
- Transparency: Board meetings are not public, but minutes of the meetings are posted to the Web site.

Executive Summary for Colorado

Report as of Site Visit on 5-18-06

Market Characteristics

- Colorado's healthcare environment includes diverse geographic regions: an urban, Front Range corridor (along the eastern side of the mountains); a wide expanse of rural and frontier counties to the east; numerous mountain resort communities; and a vast western region with a growing urban center, as well as sparsely populated rural and frontier counties.
- About 80 percent of Colorado's population lives on the Front Range.
- Most healthcare resources are located in or around Denver and other Front Range cities (e.g., Colorado Springs, Ft. Collins). Numerous small critical access and community hospitals and clinics are scattered throughout the rest of the state.
- There is not one dominant employer or health system in Colorado.
- Most large employers are self-insured; most Colorado workers are employed in small businesses. The insurance market is dominated by three or four nondomiciled for-profit companies; however, this situation varies regionally. A Colorado nonprofit health plan covers the western part of the state; another local health plan serves Medicaid.

Local HIE Activity

There are currently four community-based HIE initiatives exchanging data and in the process of gradually expanding HIE capacity in different parts of the state. These HIE initiatives vary in participation and technical models. In addition, several large physician groups are interconnected with their care partners via secure messaging. HIT and HIE are being considered within other communities.

Organization and Governance

Colorado is one of six states with an AHRQ-funded State and Regional Demonstration Project. This project, the Colorado Health Information Exchange (COHIE), is developing the standards and prototype for statewide interoperability among its four partners—Children's Hospital, Denver Health (a public hospital system), University Hospital (research and teaching hospital), and Colorado Kaiser Permanente. Viewed by stakeholders as overly Denver-centric, COHIE became part of a more broad, statewide initiative facilitated by an independent neutral Colorado Health Institute (CHI) to develop a Colorado state-level HIE initiative or CORHIO. The CORHIO will integrate the functionality developed by COHIE and provide an accountability structure for statewide engagement. Led by a multistakeholder Steering Committee, a governance workgroup is established, and efforts are under way to seat a CORHIO Board in the upcoming months.

State Involvement

- The state public health agency and a representative of the Children's Basic Health Plan have been involved as members of the CORHIO Steering Committee.

- Efforts are under way to engage the Medicaid department and the governor's office more actively, especially related to HISPC. Involving the legislature has not been a major focus other than informational briefings.
- Colorado typically does not look to state government to take the lead on innovative programs, nor are statutory and regulatory solutions desired unless absolutely necessary. Given the recent political environment and severe state fiscal constraints, CORHIO stakeholders have focused efforts on developing consensus to advance CORHIO without seeking direct policy maker involvement. However, efforts to inform and involve policy makers are expected to become more of a priority with the move to formalize CORHIO.

Financial Model

- Initial: COHIE received funding through contracts with eHI (Connecting Communities for Better Health) and AHRQ. A portion of the eHI contract supported early CORHIO organization and communication strategies, and a planning grant from a local Colorado foundation provides resources for current business plan analysis and CHI facilitation. On behalf of CORHIO, additional grants have been received for development of specific elements of interoperability and data exchange including the Privacy and Security Project (formerly HISPC) and InformationLink grants to explore population-based data exchange and the involvement of public health.
- Sustainability: CORHIO developed an initial business plan that contemplated using administrative data exchange to launch statewide exchange and generate resources to build and sustain clinical data exchange. However, there is concern that this type of model would delay clinical HIE efforts and has limited short-term feasibility as a start-up strategy given current market conditions. Market analysis is under way to explore stakeholder priorities among several lines of business including secure messaging, clinical exchange, population-based data exchange, and administrative exchange.

Operations and Technology

- COHIE is developing the technology standards that will be incorporated into CORHIO operations. Efforts are under way through the CORHIO Technology Work Group to develop pilots to test the standards in various types of exchange beyond COHIE project partners. CORHIO will be the entity to launch and maintain HIE operations for the statewide shared utility services.

HIE Policies

CORHIO plans to follow Connecting for Health's Common Framework model. They may have a federated model that somewhat relies on local communities to begin their own HIE. No legal barriers have been identified at the state level, but this situation will be further studied with the HISPC grant.

Executive Summary for Florida

Report as of Site Visit on 5-31-06

Market Characteristics

- Florida has more than 10 local health information organizations around the state that have been formed by various organizing groups—economic development organizations, philanthropic foundations, healthcare organizations, and other groups specially formed for the purpose of developing a HIE in their area whose development and progress have been accelerated and encouraged by Florida Health Information Network's (FHIN's) grant program to promote them.
- Florida has a large group of small employers, there are 261 hospitals statewide, and about 15 to 20 percent of its population is uninsured.
- Florida has a high percentage of Medicare patients, and many of them are seasonal residents.
- HCA is the largest single hospital system.

Organization and Governance

- Governance: Governor Bush established the Governor's Health Information Infrastructure Advisory Board (Board) through Executive Order, and during the last 1.5 years, it developed the concept for the FHIN. Currently, there is no consumer representative serving on the Board. Instead, a number of members represent the consumers' interests in developing a statewide health information network.
- Organization: Florida's Agency for Healthcare Administration (AHCA) currently uses a grants program to fund three types of grants that help establish and set up local HIE organizations. House Bill1409, if passed, would have statutorily created FHIN, Inc. The bill also provided a construct for governance and funding for operational activities.

Financial Model

- Initial: In fiscal year 2005-2006, AHCA received $1.5 million in funding from the state, plus two FTEs to establish the FHIN grants program and related HIT programs; $1.5 million went entirely to local HIE initiatives to do 1:1 matching, so really $3 million was invested in local HIE initiatives. This year, they received $2 million plus two more FTEs for the program, for a total of four FTEs. They also have received a small federal contract award.

- Sustainability: Although some stakeholders are considering HIE a public good and expect the state to pay for the infrastructure, FHIN, Inc. will look at ways to generate revenue streams and not be dependent on the state. Currently, stakeholders are evaluating different models, including transaction fees, membership fees, and funding opportunities with Medicaid.

Operations and Technology

- Operations: Currently, AHCA operates the grants program to help plan, operate, and train the stakeholders in the local HIE initiatives. Florida Medicaid has an e-prescribing program (Gold Standard) that distributes a PDA to physicians who are frequent prescribers. In Florida, there are concentrations of Medicaid patients with certain doctors, thus facilitating the implementation of the program in some physician offices. FHIN, Inc. also has plans to incorporate the state immunization online tracking system (SHOTS) and other state data sets.

- Technology: FHIN technical considerations are outlined in a white paper developed this year by consensus of the state's HIT community. Although technology discussions are ongoing, FHIN technical standards are described in its white paper.

HIE Policies

- Florida is contemplating several options. They anticipate that healthcare stakeholders who own patient data under current law will continue to do so, but in compliance with existing law, consumers will have access to their data, with a convenience of electronic access that makes legal rights much more meaningful. FHIN, Inc. expects to have a break-the-glass policy in emergency departments for patients who are incapacitated. State laws on privacy are being further explored.
- Legal Barriers:
    - Under Florida law, certain information held by government and quasigovernment entities is available for public inspection as public records, unless the legislature has granted an exemption. AHCA and FHIN are seeking a separate exemption for patient records held by FHIN so that there would be no question about the protected status of the records held by the FHIN.
    - Florida has a Patient Self-Referral Act, which is a mini-Stark Law, which needs to be analyzed.
    - CFR requires that Medicaid data be used only for state plan administration. They need clarification from the federal government that Medicaid data can be used by FHIN to alleviate concerns. The same clarification is needed for Medicare.
- Other Barriers:
    - Florida law and regulations require laboratories to send results to the ordering doctor and currently does not provide for an exemption for the access to an HIE. Legal barriers will be examined and solutions proposed.
    - Education will be an ongoing effort. AHCA needs to reach out to other state agencies to gain their support for the FHIN.
    - HIE initiatives have experienced some difficulty with privacy officers. AHCA and HIE initiatives are working on a HIPAA model agreement that HIE initiatives can give to privacy officers, which seems to be more of an educational issue than not.
    - Clinician resistance to work flow changes has probably slowed the adoption of EHR systems.

Executive Summary for Indiana

Report as of Site Visit on 5-28-06

Market Characteristics

Local HIE Activity:

- The central Indiana area, which has evolved to have the entire state as its mission, has a well-developed HIE initiative.
- The Michiana area (South Bend) in the northern part of state has a small group.

Payer Mix: Indiana has very few managed care organizations.

Governance

Indiana has a unique dual-governance structure based on its origins:

- INPC: In 1997, the Indiana Network for Patient Care (INPC) was formed through a multiparty data-sharing agreement, forming what we would now call a virtual HIE initiative. This agreement permits data submitted by participants to be used for treatment, research, and some public health uses. Certain minimum data must be submitted to be a participant; that is, the participant has to give data to be able to take advantage of receiving data. Regenstrief Institute, a not-for-profit research organization affiliated with Indiana University, was the proponent of the INPC, developed the software and maintains the network, and serves as the custodian of the data. The agreement established a management committee to make decisions; however, if there is a new use of the data not specified within the scope of the INPC agreement, then a formal amendment to the INPC agreement must be signed by all participants. Newer uses of the data are being contemplated, and amendments to the INPC agreement are currently being discussed. The management committee consists mainly of hospital systems, physician groups, and Regenstrief. The management committee can vote on changes in use of the network but cannot go beyond what is in the INPC agreement without consent of all participants.
- IHIE: The Indiana Health Information Exchange, Inc. was formed in February 2004 to build on Regenstrief's INPC network. Whereas Regenstrief's mission is research and improving clinical care, IHIE's mission is focused on customer services and the expansion of HIE throughout the state of Indiana. IHIE would not exist but for the efforts of Regenstrief in developing the INPC. IHIE's Board has the following stakeholders: Indiana State Department of Health, Marion County Health Department, Mayor of Indianapolis, the five large hospital systems in central Indiana, Regenstrief, Indiana University School of Medicine, the two Indiana medical societies, one community foundation, and some ad hoc members. IHIE management commented that this mix of stakeholders needs to be changed to accommodate other stakeholders that have an interest in HIE in Indiana. Each Board member has an equal vote; however, the bylaws specify that any matter directly addressing the functionality or implementation of IHIE's clinical messaging project must reflect a concurrence of at least a majority of the hospital Board members. This special voting carve-out was negotiated at IHIE's formation because of the importance of the project to the hospital members.

Funding and Financial Model

Initial Funding

- INPC—Initial funding (1997) came from grants from a wide variety of sources.

- IHIE—Initial funding (2004) came from grants and a partial prepayment of the first year's clinical messaging subscription fees by four of the five hospital systems.

Sustainability Model

- A patchwork of funding sources has sustained INPC and IHIE across time. These include grants and contracts from various sources, contracts from Indiana State Department of Health, subscription fees for services provided (e.g., clinical messaging), and software license and support fees.
- IHIE is already self-sustaining from the funding for its first project, clinical messaging. IHIE is looking to continue to add services that are of value to stakeholders and that will be self-sustaining business lines, such as the clinical quality project (a pay-for-performance reporting project that is currently in development). IHIE may also be involved in some grants in coordination with Regenstrief; however, IHIE's business model will not depend on grants for sustainability.

Operations and Technology

- Software: Regenstrief is the software developer.
- Hardware: Regenstrief is responsible for the operation of the network and maintenance of the hardware. One of the local hospitals has allowed the use of its server room for the Regenstrief and the IHIE hardware.
- Training and Support: For software that was in use before IHIE (such as emergency department access to patient data), Regenstrief trains and supports end users. For the clinical messaging project, IHIE serves as the face to the customers and trains and does first-tier support of end users, and Regenstrief provides second-tier technical support.
- Technical Model: Production data feeds in HL7 format from the INPC participants and others come in to Regenstrief's system and are processed (mapped to LOINC standard codes) and stored in separate "vaults" by data provider (e.g., laboratory and other data from Hospital A are stored in Hospital A's vault). A master patient index and common concepts dictionary are used across all the data.
- Standards: Regenstrief has been a strong developer and proponent of national standards and actually developed LOINC, which has been accepted as the international standard for laboratory results. Regenstrief also uses HL7 standard format for the data streams.
- HIE Activities: Indiana has a mature HIE.
    - Treatment: INPC enables clinical data (e.g., laboratory; radiology; transcription; admission, discharge, and transfer information; and electrocardiography) to be provided to physicians for treatment at the point of care. Regenstrief receives more than 95 data feeds from various sources. Most recently, Medicaid gave Regenstrief access to all of its claims data, which includes medication claims, for INPC uses. Regenstrief also has an agreement with RxHub to receive medication claims history.
    - Research: As mentioned, INPC data are used for scientific research. Regenstrief is developing a query tool to enable automated deidentified (as defined in HIPAA) queries of the INPC.
    - Public Health: Regenstrief is closely involved with the Indiana State Department of Health (ISDH) on a number of fronts:
        - Public health laboratories feed data into INPC (e.g., immunizations, lead tests, newborn screenings).

        - ISDH is a clinical messaging customer of IHIE or Regenstrief for delivery of its laboratory results to its clinics (e.g., HIV results).
        - Regenstrief functions as the business associate of the hospitals for the purpose of reporting certain communicable disease laboratory results to ISDH.
        - ISDH has engaged Regenstrief to establish connectivity and receive admission data feeds (e.g., chief complaint) from all hospitals in the state (funded from a CDC grant to support biosurveillance).
    - Healthcare Operations: Use of the INPC data for supporting healthcare operations is being explored in IHIE's clinical quality project (pay-for-performance reporting project). An amendment to the INPC agreement would be required for this new use.
- Intellectual Property: Some of the Regenstrief software has been released as open source, and some is proprietary (like clinical messaging software). Regenstrief owns the intellectual property.

HIE Policies

- Indiana does not impose laws more restrictive than HIPAA regarding privacy.
- The INPC agreement and IHIE's agreements similarly do not impose any extra restrictions, with the exception of research. The INPC agreement goes beyond HIPAA in that it requires institutional review board approval or waiver for all research and inviting the participant's own investigators to participate in the study. In addition, it does not allow research that would compare the participants themselves (e.g., data cannot be used to compare patient outcomes, financial information, charges to patients, etc. on a participant-by-participant basis).
- In practice, INPC does not permit just anyone to log on to the system and retrieve patient data.
    - For research, only Regenstrief personnel can access and extract data (and only after the proper approvals).
    - For treatment, access to a patient's record is limited to when the network receives electronic notice that a patient has presented for treatment and for a designated length of time thereafter (e.g., three days after discharge). Access is also limited to only physicians who are allowed access to the specific facility where the patient presented for treatment.
- In INPC, sensitive data, such as psychotherapy notes and alcohol and drug abuse treatment center data, are specifically restricted from being sent to the INPC network.
- Regenstrief and IHIE are business associates of the covered entities that participate in the HIE.
- Indiana law relating to HMOs is a barrier to using payer claims data for research.
- One significant barrier to including smaller data providers in the HIE effort is that the cost from the vendors for the interface modification or module to generate HL7 messages out of their systems is prohibitive. That is, the particular software vendor (laboratory, EMR, etc.) wants to charge full price for turning on a feature or adding a new module to generate the HL7 feed out of its system, and they want to charge this same full price to every small hospital, even though it is the same interface for each. IHIE has been trying to break this barrier by talking to the vendors but are currently making no headway. Although not a legal barrier, this is a significant obstacle to

enabling HIE throughout the state, especially in the rural areas where there are smaller hospitals.

- IHIE and Regenstrief believe in being open with stakeholders; however, the management meetings are not open to the public, and the minutes of the meetings are not open to the public. Regenstrief has released the INPC data-sharing agreement publicly, although recent amendments have not been published yet. IHIE believes that they are competing to some extent with other service vendors and that publicly making financial and strategic plans open to the public would be harmful to IHIE.

Executive Summary for Maine

Report as of Site Visit on 5-10-06

Market Characteristics

- The only HIE activity in Maine is statewide.
- Maine's population is concentrated in the Portland, Lewiston, and Bangor areas. Some parts of Maine are very rural and have limited telecommunications available.
- Because of the size and market of Maine, usually one player is dominant for a particular stakeholder constituency (e.g., Anthem is the dominant private payer, and there is only one medical association). Although this situation makes it easier for convening the healthcare leaders in the state, it makes it more difficult to get the attention of national stakeholders.
- Maine is mostly a small employer state. The state is the largest employer.
- Maine has a large Medicare population compared to that of other states.
- Medicaid has had recent problems with timeliness of its claims processing, and there is currently negative sentiment among healthcare providers toward Medicaid. Because of Medicaid's focus on improving its own systems and unfilled senior level staff positions, Medicaid is not currently actively involved in the statewide HIE effort.

Governance

- The Maine Health Information Center (MHIC) was the development coordinator for HealthInfoNet (formerly called the Maine Health Information Network Technology [MHINT] Project) and currently provides project and fiscal management services to HealthInfoNet.
- A full-time Executive Director was hired in June 2006.
- Maine spent a significant amount of time and energy on thoughtfully convening stakeholders, conducting a feasibility study, developing a plan for statewide HIE, and selecting a Board (beginning early in 2004).
    - Several committees met during 2004-2005, including Consumer Stakeholder Group, Governance Group, Public Health Data Workgroup, Privacy/Security Workgroup, and Technology Committee. These committees are in the process of being reviewed and updated to remain aligned with the progress of the organization.
    - Individual state leaders were recruited for the Board positions rather than having organization-designated slots.
    - Bylaws have been approved, and HealthInfoNet has been incorporated. A 501(c)(3) application is being prepared.
    - Governance has strong consumer privacy advocate involvement: there are two positions on the Board, the bylaws have specific privacy or security provisions, supermajority vote is required for new use of the data or other privacy or security issue, and a standing consumer committee is established.

Funding and Financial Model

Initial Funding

- Private foundations, payers, hospitals, state government, and others have provided broad-based funding to date.
- The Maine Health Access Foundation has awarded a $1 million challenge grant.

- Federal money has not been a priority to date, although HealthInfoNet has received a contract that will help identify barriers to HIE.
- HealthInfoNet received an award from RWJF to participate in the Information Links project focusing on public health information needs.
- They are currently in a fundraising campaign for the pilot phase.
- They are also researching the possibility of a state bond package.

Sustainability Model

- They are just beginning to explore ideas for sustainability or a financial model.
- A Business/Financial Plan workgroup has been assigned.

Operations and Technology

- Technical Model: A statewide clinical network (centralized repository and electronic master patient index (EMPI or MPI)) is being planned. Two finalist vendors have been selected, and negotiations are under way. Access to patient data by clinicians would be through their existing EMRs, if available, or directly through HealthInfoNet. HealthInfoNet will use an application service provider model. An interface for reporting public health required information is also being developed.
- Standards: They plan on mapping laboratory to LOINC, using HL7 for data feed from data sources, using other available standards (e.g., ICD-9 for diagnoses), and using XML for feeding data into clinicians' EMRs eventually.
- HIE Activities: A committee has developed a listing of data types that would be of value to clinicians. Priorities of this data are being reviewed for the pilot. The pilot period is expected to last 24 months, with the first six months devoted to project planning (beginning now), the second 12 months will involve initially patient data being exchanged between two hospitals, and then other hospitals phased in during the period, followed by the last six months to be used for evaluation (metrics to be determined). Thus, the planned target start date for the pilot's first exchange of data is January 2007.
- Intellectual Property: Maine does not plan to require ownership of intellectual property developed for Maine.

HIE Policies

- Privacy: Maine engaged consumers early. The Consumer Committee made a recommendation that an opt-in approach be adopted. However, no decision on this issue has been made yet, and a variety of privacy options are currently being explored.
- Legal Barriers: State law and other barriers are being explored.
- Transparency: All activities are communicated openly, and meetings are open to the public.

Executive Summary for Massachusetts

Report as of Site Visit on 5-15-06

Market Characteristics

- Most healthcare in the state is in the Boston metropolitan area within the Highway 495 loop. Western Massachusetts is largely rural.
- Three large integrated delivery networks (CareGroup, Partners, and Caritas) cover a significant portion of the entire state's population.

Governance

The governance structure has grown out of various efforts and initiatives in Massachusetts. It is a combination of efforts from four entities that compose a virtual state-level HIE initiative. Close communication and coordination is achieved because many of the same people are on the Boards of these four organizations.

- MHDC was formed in 1978 by state public and private healthcare organizations. MHDC serves as a convener, lobbying, and policy organization.
- MA-SHARE was formed in March 2003 and is a wholly owned subsidiary (sole member LLC) of MHDC. MHDC appoints the MA-SHARE Board members. MA-SHARE serves as the grid for clinical operability for the state and plans connect the local HIE efforts with an RLS, mentioned in more detail here.
- MAeHC was formed in 2004 with $50 million funding from payers. Its three-year goal is to provide EHRs to 600 clinicians and develop a sustainability model to continue its efforts to ensure every clinician in the state has an EHR.
- NEHEN was created in 1998 by payers and providers in the community for financial data exchange between payers and providers.

Funding and Financial Model

Initial Funding

The various entities in Massachusetts have received initial funding from a variety of sources:

- MAeHC received $50 million from payers.
- MA-SHARE received $3.4 million from grants from stakeholders.
- MA-SHARE is a market for the NHIN architecture contract. They have also received eHealth Initiative funding, AHRQ, Markle Foundation, and other grants.

Sustainability Model

The various entities in Massachusetts have different sustainability models:

- MA-SHARE has implemented a subscription fee model for ePrescribing ($50,000-$100,000 per year depending on size) and plans to do the same for clinical data exchange services. They believe that "collaborating to jointly invest in fixed costs to reduce overall costs for all is a more effective model than transaction fees." Their approach is to create a utility to do several things and expect that entities will pay a membership fee in relation to the value derived from using MA-SHARE services. MA-SHARE plans to begin to receive revenue in 2007 and be self-sustaining in 2008.
- MAeHC is awarding $50 million to three regional pilot programs with the requirement that the local HIE initiatives become self-sustaining by 2008. MAeHC is developing a model to sustain itself after 2008.

- NEHEN has a well-established financial model of payers paying a membership fee (tiered) to participate in the administrative data exchange.

Operations and Technology

- Software: CSC is the program manager, provides development services, and integrates commercial products.
- Hardware: All hardware is currently owned by stakeholders and is housed at their locations. MA-SHARE and NEHEN are deploying shared hardware for selected central functions in 2006.
- Training and Support: MA-SHARE and NEHEN provide training to trainers. MAeHC provides direct end user support.
- Technical Model: MA-SHARE hosts the RLS and creates all the clinical exchange gateway software that resides at each provider site and enables peer-to-peer data exchange. The quality data warehouse is centralized, but is deidentified (as defined in HIPAA).
- Standards: MA-SHARE does not plan to do any mapping or coding of laboratory results, but rather have the data providers map them at the local level. Thus, when the RLS pulls the data, the laboratories would already be standardized. MA-SHARE uses HITSP-recommended standards and is very active in national standards committees.
- HIE Activities:
    - ePrescribing—Statewide ePrescribing gateway infrastructure connecting SureScripts, RxHub, payers, and providers was deployed in May 2006. They are in production with 700 clinicians at Beth Israel Deaconess/CareGroup. Partners are to be added in August 2006.
    - Clinical Data Exchange—Current preproduction infrastructure for regional RLS has been under way since 2004 and is populated with 500,000 patients. MA-SHARE plans to go live with laboratory, allergies, problem lists, and medication history by the end of 2006.
    - Medication History—A pilot project called "MedsInfo" was conducted in 2005. The goal was to share medication history for a patient with the provider. Building on the lessons learned from the pilot, eRx Gateway was developed and went live in May 2006. eRx Gateway does provider identifier mapping to SureScripts and RxHub centrally.
    - Public Health—Several local hospitals participate in the CDC's BioSense project and transmit emergency department chief complaint data to the CDC every 15 minutes. Live since 2003, Boston-based emergency departments provide demographic and discharge data to the State Department of Health (AEGIS project).
    - EMRs—MAeHC's role is to provide EMRs in physicians' offices.
    - NEHEN is an entity that shares administrative data between payers and providers (e.g., eligibility checking). NEHEN and MA-SHARE share software components and have overlapping staff. NEHEN will do the national provider identifier mapping for the region centrally.
- Intellectual Property: MA-SHARE believes in open source for all its software and plans to release all as open source

HIE Policies

- Privacy: MA-SHARE believes in an opt-in approach per institution requiring the documented opt-in (consent) by the patient at the point of care. These consents are already being collected in MAeHC communities.
- Legal Barriers: State law prohibits a payer from sharing medication history related to mental health, substance abuse, and HIV. The MedsInfo pilot project was required to filter the medication data to block sharing of this type of data. A committee was set up to review new drugs that came on the market to see whether the filter needed to block them, which also required blocking drugs that had dual uses (e.g., for HIV and for some other disease). The eRx Gateway project replaces MedsInfo and has gotten around this legal barrier by obtaining the medication history from the pharmacies instead of the payers. Other barriers are also being explored.
- Transparency: All activities are communicated openly, and minutes from meetings are published on the Web site; however, the meetings themselves are not open to the public.

Executive Summary for Rhode Island

Report as of Site Visit on 5-17-06

Market Characteristics

Rhode Island is a very small state with one basic market, and there are currently no other HIE efforts in the state. There are 15 hospitals in the state and about 420 practices.

Organization and Governance

Rhode Island Quality Institute (RIQI) was founded in 2002. Currently, the State Department of Health is the grantee for the AHRQ money, and RIQI is the lead on governance issues related to HIE. RIQI has a Board that meets monthly and committees that meet every two to six weeks. RIQI represents multiple stakeholders including the QIO and consumer advocates. Each stakeholder is granted one vote. Four of the committees are chaired or co-chaired by government individuals. They have refined their governance structure and currently have committees formed and discussing various HIE policies.

Financial Model

Initial: RIQI's initial funding came from stakeholder donations, SureScripts, and a few small grants. Currently Blue Cross/Blue Shield of Rhode Island, Lifespan, CVS Pharmacy, and the Rhode Island Health and Education Building Corporation are the major funders outside the $5 million AHRQ contract. However, recently the governor requested the legislature approve a bond fund that would serve as a vehicle to generate $20 million that would go to RIQI for HIE.

Sustainability: RIQI has four sustainability concepts that they are currently discussing, with an understanding that the final result will likely be a combination of two or more concepts. The first concept is based on a notion of public good and would spread the costs out over the entire population. Because physicians get only a small benefit, and more significant benefits go to the payers, including self-insured employers, federal government, state government, and private employers. RIQI is looking at the HIE infrastructure as a public good. The second concept is a combination of "who benefits" and revenue generated from the HIE. This concept involves receiving payments from those who benefit from the system (initially determined by using existing models developed by the Center for Information Technology Leadership) and receiving payment for sale of analytics and other value-added services of the HIE. The third model is based recapture of administrative waste, streamlining transactions between providers and payers. The fourth model has not been publicly released, as it is under development, but is based on the idea of a value-based Rhode Island healthcare Web portal.

Operations and Technology

Technical: The model was developed by the technical solutions group and data-sharing partners group. Their initial planned model includes an MPI and data storage model that stores the data by type rather than source. For example, laboratory results from all data sources would be stored in a laboratory file, medication history would be stored in a medication history file, radiology would be stored in a radiology file, and so on. The Department of Health has an RFI out to see if it is feasible or if there is a better solution.

Standards: The AHRQ contract requires RIQI to identify the standards they will be using by the end of the year. They will be using HL7 version 2.3, and they plan to map laboratory data to LOINC.

Operations: RI has three main laboratories, KidsNet (an online immunization record available to various stakeholders), and a few other efforts that they plan on initially plugging in to the HIE. Also, they were the national beta test site for SureScripts e-prescribing in 2003.

HIE Policies

RIQI has decided that the standards will be transparent and open, but they are in the process of working with consumers and providers to resolve privacy and security issues. They expect to make headway in these areas as they move forward to identify barriers to HIE.

Executive Summary for Tennessee

Report as of Site Visit on 5-22-06

Market Characteristics

- The state has three main regions—eastern, central, and western—with very different cultures and populations.
- There are four local HIE initiatives:
  - Mid-south eHealth Alliance (Memphis)—formed in 2004
  - CareSpark (Appalachian area)—formed in 2005
  - IVHIN Knoxville—formed in 2003
  - Nashville—just starting discussions

Governance

- Governor's Executive Order 35 established an Advisory Council, whose members are appointed by the governor. Since this report, the Council has been announced and includes 16 members representing Tennessee's provider community, employers, local HIE initiatives, payers, and consumers. They expect the quorum to be as low as seven by design to encourage participation. The Advisory Council will be composed of representatives from all the local HIE initiatives, top three payers, top four employers, academia, provider groups, PBMs, consumers with no healthcare experience, and one national expert.
- The Advisory Council plans to provide guidance to the governor and the legislature and would attempt to eliminate barriers at the state level but not to lobby.
- The Advisory Council plans to function as a convener of local HIE initiatives and would assist in resolving any disputes between local HIE initiatives.
- They are still in the process of defining their role at the state level at this time.
- They anticipate forming workgroups to address specific issues.
- The inaugural meeting took place on June 26, 2006. The meeting was chaired by Governor Bredesen and Commissioner Goetz.

Funding and Financial Model

Initial Funding

- State funded the Advisory Council.
- Local HIE initiatives have funding from different sources.

Sustainability Model

- The sustainability financial model is currently confidential and is being circulated to the local HIE initiatives for comments. They plan to incorporate responses from the local HIE initiatives. We are allowed to disclose the general concepts, which are that $X per month proportionate to the stakeholder's value received is paid by a stakeholder (type yet to be named) to the state-level HIE hub, of which Y percent is earmarked to be spent on connection to physician offices and Z percent for academia.
- The initial focus is on State TennCare (Medicaid).

Operations and Technology

- Software: There is no software developer at the state level. The state has an RFP out now for an MPI, but it is one for all state agencies, not just HIE. The state MPI will allow a unified view from various state agencies.
- Technical Model: Unknown at this time.
- Intellectual Property: There is no intellectual property at the state level; however, the state holds the intellectual property from any initiative that the state is funding.

HIE Policies

- Tennessee has not decided on privacy aspects.
- Legal Barriers:
    - Barriers to HIE are in the process of being identified.
    - One known barrier is the law subjecting an entity to open records law if it receives a state grant that is more than 30 percent of its income. They are trying to introduce legislation to carve out an exception for nonprofit HIE efforts.
- Other Barriers:

  Physician practices with fewer than 10 physicians and outside an urban area do not typically have Internet access.
- Transparency: Advisory Council meetings are not public because of their advisory nature. However, an executive summary will be posted on the eHealth Web site.

Executive Summary for Utah

Report as of Site Visit on 5-9-06

Market Characteristics

Regions:

- Of its 2.7 million residents, 2.3 million live in the Wasatch region (around the Great Salt Lake and in the valley to the east of it). About half of the other residents live in the St. George region in the southwest part of the state. The rest live in regions officially designated as rural or frontier.
- Residents from northern Nevada, southern Idaho, eastern Oregon, and western Wyoming fly in via helicopter or drive in for tertiary care services. Residents in the eastern part of Utah find it easier to obtain healthcare services in Grand Junction, CO. The St. George region provides healthcare to both Utah and southern Nevada residents, and telehealth services supplement the primary care delivered in the rural and frontier regions.

Population:

- In the eastern part of the state sits a large Indian reservation. In addition, southern Utah holds the northern portion of the Navajo reservation.
- The Church of the Latter Day Saints members throughout the state account for a significant percentage of the population.

Local HIE Activity: There is none other than the Utah Health Information Network.

Telecommunications Infrastructure: Rural hospital telecommunications infrastructure is good thanks to the Utah Telehealth Network efforts. Rural hospitals are served better than those in other states. In addition, schools have excellent telecommunications infrastructure. However, other rural entities are less well served.

Healthcare Entities:

- There are approximately 50 hospitals; between 7,000 and 10,000 physicians; and many large insurers, including Select Health, Public Employees Health Plan, Blue Cross/Blue Shield, and United Health Care.
- The major research organizations are the University of Utah and Intermountain Health Care (IHC).
- IHC is the dominant integrated delivery network and the second largest employer in the state.

Governance

- Formed in 1993, UHIN is a 501(c)(6) (membership association).
- The model for administrative data exchange is voluntary membership and the member pays a membership fee. Members can choose to purchase a seat on the Board ($35,000).
- The Board is run by consensus.

Funding and Financial Model

- UHIN raised start-up funds by allowing interested companies to purchase a general membership (*i.e.*, a seat on the Board of Directors).
- The model for administrative data exchange is that membership fees cover operational costs and more.

- Administrative data exchange has a clear return on investment, and UHIN has even been asked to perform administrative data exchange outside Utah.
- A credentialing project is anticipated to generate a revenue stream from payers and hospitals for the service, once it is up and running.
- UHIN is still working on the sustainability model for clinical data exchange. The pilot is free. They are not committed to doing clinical exchanges during the pilot. The goal is to create a product for clinical exchanges that will be self-supporting.
- UHIN only offers services that bring value to members (*i.e.*, that members are willing to pay for).

Operations and Technology

- Services:
  - UHIN has had administrative data exchange operational for some time.
  - UHIN is exchanging credentialing data for physicians, for both payers and hospitals.
  - UHIN is close to offering an automatic accounts posting tool for small providers.
  - UHIN is working on starting a pilot project for clinical data exchange.
- Software: UHIN operates a service-oriented secure Web-based hub.
- Technical Model: Post office model; there is no data repository for administrative data. UHIN does not plan on having a data repository for the clinical data exchange either.
- Standards: Standards are created at the request of the community through the UHIN Standards Committee. Standards require a unanimous vote to move to the Board of Directors for final approval. UHIN standards for administrative data exchange are also adopted by the Utah Insurance Commissioner for incorporation into State Rule. For clinical data exchange, UHIN will be piloting both formatted (HL7 and NCPDP) and unformatted (PDF, TIF) messages. UHIN will be distributing a free tool to providers and payers (UHINT) to allow them to send and receive these messages for minimal IT development costs.

HIE Policies

- For administrative data exchange, there are no patient matching issues.
- UHIN's first goal for HIE of clinical data is to move existing paper, phone, and fax exchanges to EDI. Thus, the hospital can send a discharge summary to a physician via UHIN, a physician can receive a laboratory result, and so on. In this environment, Utah does not envision any immediate privacy challenges.
- UHIN is also exploring exchanging medication histories, which is a new type of information and will require careful thought about the new privacy issues entailed in it.

Appendix B—Worksheets

Worksheet 1-1. Market Characteristics

(in no particular order)

MARKET CHARACTERISTIC	FINDINGS IN MY STATE	POTENTIAL EFFECT ON STATE-LEVEL HIE	COMMENT
Number or prevalence of local HIE organizations or pre-existing HIE activity locally			
History of collaboration among healthcare entities within the state versus a very competitive market with low collaborative spirit			
Whether there are local markets or regions that significantly vary in their needs (e.g., one has a higher Medicaid population, whereas another has a higher Medicare population with chronic disease)			
Distribution of urban versus rural			
Size of the state and population distribution			
Health of the state economy (e.g., Medicaid crisis or budget surplus)			
Whether the state's local markets are contiguous with other states, which may require coordination with neighboring states			
Number or prevalence of managed care organizations (e.g., could influence who bears the risk and who benefits from the financial incentives)			
Whether one or a small number of payers are dominant (e.g., market share of payers), which could affect how difficult it will be to implement certain services (includes large employers, health plans, etc.)			
Whether one or a small number of health systems or hospitals are dominant (e.g., market share of hospital systems)			
The proportion of large physician practices to small physician practices			
Availability of broadband Internet access			
Prevalence of use of EHR systems in the physician office			
Prevalence of the use of EHR systems in hospitals			
Number of medical research organizations			
Patient population demographics			
Population health status (e.g., prevalence of certain disease or conditions)			
Attitude toward privacy (if known)			
State government initiatives through the governor’s office, state agencies, or state legislation			
Other			

Worksheet 2-1. Key Stakeholders/Advocates

(in no particular order)

No.	Type of Stakeholder	Organization	Individuals	Feasibility
1	Hospital or health systems, in general			
1.1	Individual hospital or health system			
1.2	Hospital association			
1.3	Safety-net hospital			
1.4	Small hospital			
1.5	Large health system or integrated delivery network			
2	Clinicians, in general			
2.1	Medical society			
2.2	Large group practice			
2.3	Small or solo physician practice			
2.4	Primary care			
2.5	Specialty care			
3	State government, in general			
3.1	State Department of Health			
3.2	Governor			
3.3	Healthcare facility licensure agency			
3.4	Medicaid			
3.5	State legislator			
4	Payers (nongovernmental)			
4.1	Self-funded plans			
4.2	HMOs			
4.3	Private payers			
4.4	Other			
5	Nursing and health professional associations			
6	Long-term care facilities			
7	Pharmacy Benefit Management (PBM) or pharmacy			
8	Quality and safety organizations			
8.1	QIO			

8.2	Patient safety organization			
9	Ancillary health-related services (e.g., laboratories, imaging centers)			
10	Consumer, in general			
10.1	Privacy advocate			
10.2	Healthcare user without expertise			
10.3	Organizations representing public interest or consumer groups related to disease (e.g., American Diabetes Association)			
10.4	Other organization (e.g., American Association of Retired Persons)			
11	Local HIE and/or geographic representatives			
12	Employers or business groups			
13	Academia or other research entities			
14	Vendors			
15	National expert from outside the state			
16	Local government, in general			
16.1	County or local health department			
16.2	Mayor or other elected official			
17	Federal government, in general			
17.1	HHS or Centers for Medicare or Medicaid Services (CMS) regional representative			
17.2	Veterans Affairs			
17.3	Centers for Disease Control (CDC)			
18	Other individual with heavy business experience (e.g., banking executive)			

Worksheet 2-2. Drivers to Action/Triggering Events

(in no particular order)

DRIVER OR CATALYST	RISK	REWARD	TIME FRAME
Governor's Executive Order			
Legislative mandate			
Grant or other money available for statewide HIE			
Summit or ongoing meetings of healthcare leaders			
Medicaid crisis			
Local leadership impetus			
Self-interest of the organizations seeking value and Return on investment			
Entrepreneurs			
Pressure from major employers			

Worksheet 3-1. Role of State-Level HIE Initiative

(in no particular order)

POSSIBLE ROLE OR FUNCTION	ROLE	IMPORTANCE IN MY STATE	FEASIBILITY	STATUS
Convene, educate, and innovate:				
Convener of stakeholders	Essential			
Education and advocacy (use as bully pulpit or to provide proactive guidance, when needed)	Essential			
Track federal policy, proposed legislation, and federal strategic direction and then communicate that with local HIE efforts and work together to review state and local strategic direction in light of the federal direction. (*Work together with policy makers, where possible, to provide input and shape policy*)	Essential			
Serve as a source of information about local HIE efforts, if applicable	Essential			
Encourage the adoption of HIT and/or EHRs to support the infrastructure capacity for statewide HIE	Essential			
Facilitate consumer input, monitor public opinion, and help communicate with the public	Optional			
Coordinate, develop, and enforce policy, standards, and legislation:				
Promulgate standards to apply to all HIE efforts in the state and/or vendors doing business in the state. (*Suggest accomplishing through consensus*)	Essential			
Lead in development of public policy for statewide HIE goals. (*Deciding how to use data may be viewed as a local HIE issue versus a state-level HIE initiative*)	Essential			
Identify statewide barriers to HIE, develop plan to address, advise on legislation or other actions to remove barriers, and identify and remedy gaps in HIE service (e.g., underserved areas). (*Not lobbying per se but rather an advisory or educational role*)	Essential			
Enforcement of HIE policy	Optional			
Gain efficiencies within state government:				
Help the various state government agencies share their information more effectively and efficiently and avoid making complex internal changes	Optional			

Worksheet 3-1. Role of State-Level HIE Initiative (continued)

POSSIBLE ROLE OR FUNCTION	ROLE	IMPORTANCE IN MY STATE	FEASIBILITY	STATUS
Connect with communities, neighboring states, and the federal government:				
Neutral forum between local HIE efforts and/or stakeholders to resolve disagreements, but only as they relate to the statewide effort. (*Avoid getting involved in competition issues*)	Essential			
Link state (and local HIE efforts, if applicable) to nationwide HIE efforts (e.g., NHIN). (*Does not preclude local HIE efforts from direct NHIN involvement*)	Essential			
Negotiate, facilitate and operate:				
Negotiate arrangements with vendors for purchase of products or services for local HIE activities and exercise leverage to facilitate meetings	Optional			
Facilitator of funding of local HIE efforts, if any (not necessarily be the source of funding but rather assist and facilitate funding)	Optional			
Technically link local HIE efforts together, if applicable	Optional			
Provide technology services or other assistance to areas of the state not well served by local HIE efforts, if applicable	Optional			
Serve as central hub for statewide or national data sources and shared services	Optional			
Provide other administrative support and serve as an information resource to local HIE efforts (e.g., legal support, grant availability, grant writing and administration, technical services, options for technical architecture, list of possible vendors)	Optional			

Worksheet 3-2. Role of State Government

(in no particular order)

POSSIBLE ROLE OF STATE GOVERNMENT	IMPORTANCE IN MY STATE	FEASIBILITY IN MY STATE	STATUS
Public health: define public health uses for HIE including communicable disease reporting, outbreak monitoring, and population quality and disparity measurement			
Public health: set standards for aggregating and using population data			
Payer (Medicaid, pharmaceutical assistance programs, public employee benefit) that sets incentives to spur HIE (not just HIT)			
Fund pilot projects			
Fund for the long term (state infrastructure)			
Loan guarantor (e.g., possibly use low interest bonding authority)			
Convene individuals, organizations, and state agencies within the state			
Foster collaboration among regions and organizations within the state or among states			
Grant recipient and administrator who subcontracts with local HIE efforts			
Promulgate and support legislation related to HIE barriers			
Policy development related to HIE barriers			
Issue Executive Orders that promote HIE, including removing barriers			
Create a strong regulatory and administrative climate for the improvement of health			
Coordinate with neighboring state governments			
Issue guidance and position papers to clarify any issues			
Promulgate and support legislation and polices to mandate certain reporting			

Worksheet 3-2. Role of State Government (continued)

POSSIBLE ROLE OF STATE GOVERNMENT	IMPORTANCE IN MY STATE	FEASIBILITY IN MY STATE	STATUS
Promulgate and support legislation and policies to mandate standards			
Set standards through purchasing requirements and requests for proposals (e.g., requiring non-state-owned institutions to communicate electronically with state institutions, with careful consideration of the practical effect on the industry)			
Expand the scope of authority of existing statewide or regional healthcare delivery governing structures			
Technically connecting local HIE efforts, if applicable			
Incorporate data sharing into state institutional work flow (e.g., making Medicaid claims data available for HIE)			
Use influence as a large employer to affect change and be an early adopter or participant in HIE			
Take advantage of state action immunity to allow activities to benefit the state-level HIE initiative that would otherwise be prohibited (e.g., antitrust)			
Represent citizens of the entire state and ensure safety net for vulnerable populations (e.g., rural, uninsured, underserved)			
Communicate with and educate consumers			
Educate and certify health practitioners through universities and community and continuing education and through licensing requirements			
Ensure that any antitrust or other unlawful activity is avoided and support proper collaborative efforts			
Create voluntary alliances to support new initiatives in healthcare research, education, prevention, care delivery, and public health			

Worksheet 4-1. Principles for Choice of Legal Entity

(in no particular order)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
1	**If the state-level HIE initiative decides to form a legal entity, a not-for-profit corporation is recommended.** The state-level HIE initiative may begin as collaborative with little formal structure, but greater formality will be required as its functions and scope of operations and influence grows. Because the organization must secure support from the public sector and from other nonprofits and will most likely need to secure funding through grants, the not-for-profit form will be most advantageous. The specific tax exemption of the nonprofit corporation should be decided with the advice of legal or tax counsel. A full understanding of the implications of nonprofit status (e.g., requirements for financial disclosures, restrictions on certain activities) should also be explored with legal and tax counsel.		
2	**To the extent feasible, consider the future vision for the organization when deciding on entity form.** Designing the entity is a deliberative process and discussion should begin early. The corporate form may evolve across time as roles and functions adapt; for example, a nonprofit may form a for-profit subsidiary for some purposes.		
3	**It is not advisable for the state-level HIE initiative to be a state agency, but creating an entity by statute, or otherwise as a result of state action, is acceptable, as long as the governance is balanced public-private governance (that is, not weighted heavily toward government).** Ensuring balanced public-private governance will aid in encouraging stakeholder buy-in and establishing an entity that can be responsive.		

Worksheet 4-2. Choice of Legal Entity Analysis

(in no particular order)

TYPE OF LEGAL ENTITY	PROS	CONS	FEASIBILITY
Not-for-profit 501(c)(3) charitable organization			
Not-for-profit 501(c)(4) social welfare organization			
Not-for-profit 501(c)(6) mutual benefit organization			
Virtual HIE that is linked contractually but with no separate new entity			
Quasigovernmental entity			
State agency			
Partnership or limited liability corporation (LLC) pass-through entity			
Special joint powers authority			
Cooperative			

Worksheet 4-3. Principles for Governing Body Composition and Structure

(in no particular order)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
Selection and Representation			
1	**Governance of the state-level HIE initiative is critical to the effectiveness of the organization.** Careful thought and effort should be taken to ensure that the governance structure reflects the balanced interests of the key stakeholders. However, it was noted that those who are financially supporting the HIE effort may demand greater representation on the governing body.		
2	**Senior leadership on the governing body is necessary for the state-level HIE initiative to accomplish its goals.** "C-suite" directors will have experience in governing and be able to make decisions that commit their organizations (e.g., financial and resource commitments). The governing body is responsible for setting strategy, securing funding, and exercising oversight of all operational work. The participation of these senior-level representatives is necessary to convey the high-level status of the governing body and to gain the highest level of experience and expertise.		
3	**Governing body composition should be sized to get work done and include all critical stakeholder interests; mechanisms for participation should be designed to engage those who may not have a governing body seat**. Stakeholders must have a mechanism for meaningful participation, but, at the same time, the governing body must be sized to be workable. Workgroups and subcommittees are common ways to include non-governing body members in the work of the organization.		
4	**Governing body composition must have balanced stakeholder representation.** Be careful not to be held hostage by financial supporters. For states with multiple local HIE efforts, consider including the local HIE leaders on the governing body.		

Worksheet 4-3. Principles for Governing Board Composition and Structure (continued)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
Selection and Representation (continued)			
5	**Appointments should be made by the governing body on the basis of the needs of the organization. Stakeholder organizations may nominate qualified representatives but should not have the authority to appoint their own representatives or pass on a seat**. The governing body should make appointments on the basis of the skills and competencies needed to carry out the work. Organizations should not own seats or designate their own representatives without explicit action by the governing body.		
Governance Conduct			
6	**Rules of engagement for stakeholders must be set early and administered consistently**. A tone of collaboration must be set, and governing body members should, to the extent possible, leave their own proprietary agendas at the door to encourage the growth of the larger cooperative effort.		
7	**The formative governing body must commit to putting in the time and staying in place until the formative work is done**. Stringent rules for minimum required participation are needed, particularly in the early period. A clear understanding of expected duties by the governing members at the outset is important because early turnover could compromise progress. The role of governing body members will be determined by the building blocks the state-level HIE initiative decides to use.		
8	**The processes for governing body development and selection, as well as participation in other volunteer roles, must be explicit and transparent**. Although formative governing bodies, workgroups, and committees may be composed of those who are championing the state-level HIE initiative, a transparent mechanism for participation must be put in place early to avoid disenfranchisement of stakeholders.		

Worksheet 4-3. Principles for Governing Board Composition and Structure (continued)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
Governance Conduct (continued)			
9	**Bylaws and other establishing documents should be designed to allow reasonable flexibility to the extent permitted by law so the organization may adapt as early lessons are being learned**. Bylaws should contain only minimum language on corporate purposes (*e.g.*, for improvement of clinical care, medical research and education), to the extent possible. Bylaws should address voting rights (*e.g.*, quorum, percentage required for decision) but should not be so restrictive as to inhibit action.		
10	**State-level HIE initiative governing bodies must follow all established practices for legal and effective governance**. The behavior of the governing body will make or break the organization. Governing bodies must be scrupulous in ensuring that their members avoid all conflicts and dualities of interest, including the perception of same. They must also engage in practices that continuously improve their effectiveness. Allowance should be made for removing governing body members for cause (*e.g.*, failure to carry out their fiduciary obligations as a director, undisclosed conflicts or dualities of interest, or failure to attend meetings).		
11	**It is imperative that the governing body members serve the interests of the state-level HIE initiative by thinking above their own organizations' immediate interests and holding to the vision and the long-term goal of healthcare data sharing statewide**. It is common for governing body members to have some inherent interest in the state-level HIE initiative's activities because they are often stakeholders. In particular, if vendors or other organizations providing services to the state-level HIE initiative are voting members of the governing body, direct contractual relationships with such organizations should be carefully monitored and scrutinized to ensure a fair and equitable arrangement for all parties is concluded.		

Worksheet 4-3. Principles for Governing Board Composition and Structure (continued)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
Governance Conduct (continued)			
12	**The needs of the organization will likely change over time, and the governing body may need to undergo a transition to remain effective**. The state-level HIE initiative will evolve in response to market, technology, political, financial, and other factors. Having a periodic (e.g., annual) review and evaluation plan for assessing the governing body effectiveness is recommended. Term limits, staggered terms, and other mechanisms for review and change in governing body members should also be considered.		
Staff and Legal Counsel			
13	**Legal counsel to the entity should participate in meetings of the governing body but not serve as a director**. Having the organization's attorney attend the governing body meetings helps ensure legal guidance early and throughout the process. The state-level HIE initiative may be composed of competing entities; thus, one crucial governance issue is how to deal with antitrust issues.		
14	**Role of state-level HIE initiative staff in good governance is also an important component to success**. State-level HIE initiative staff should: (a) plan meaningful work to engage the governing body, (b) continually communicate the value of being on the governing body, and (c) educate governing body members one-on-one, when possible, to ensure all are on the same level of understanding on a topic.		
State Government			
15	**Appropriate involvement in governance from state government representatives is necessary, but governance should not be controlled by a state agency**. Government representatives should not have majority say or exert undue influence because this may run counter to the need for strong private sector leadership.		

Worksheet 4-3. Principles for Governing Board Composition and Structure (continued)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
State Government (continued)			
16	**Elected government officials should serve only if their political tenure and status will not compromise the long-term focus of the organization. Similarly, individuals appointed to the governing body by the governor, or through other governmental process, should be committed to follow the organization's vision**. States vary in government structure and in whether some positions are elected, appointed, or hired. Due consideration should be given to the potential effect on the state-level HIE initiative. A plan should be in place for weathering changes in political leadership.		

Worksheet 4-4. Principles for Transparency of State-Level HIE Initiative Actions

(in no particular order)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
1	**Transparency is important, but practices will vary depending on the role and the stage of development of the state-level HIE initiative.** Practices range from full open meetings with all activities publicly disclosed to private meetings with minutes and other activities fully or partially disclosed to the general public (e.g., confidential financial or procurement information withheld) to private meetings with limited or no information available to the general public but openness and transparency between stakeholders.		
2	**Open records law trumps, if applicable**. A state-level HIE initiative may be subject to state open records law if it is organized in a certain manner (e.g., more than 50 percent of entity's revenue comes from state grants or contracts).		
3	**Even in the absence of law, full transparency with the critical stakeholders is desirable to gain broad stakeholder support and engagement**. Successful state-level HIE initiatives operate for the public good and have an inherent obligation for accountability.		

Worksheet 4-5. Transparency Approach Options

(in no particular order)

	TRANSPARENCY APPROACH OPTIONS	PROS	CONS	FEASIBILITY
1	Full open Board meetings and all activities are publicly disclosed.			
2	Private Board meetings but minutes of meetings and other activities are fully disclosed.			
3	Private Board meetings but minutes and other activities are disclosed with some exceptions (e.g., financial information, vendor proposal review, proprietary activities).			
4	Private Board meetings are open among stakeholders but have limited or no communication of activities or financial information to the public.			

Worksheet 5-1. Principles for Initial Funding

(in no particular order)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
1	**Understand the goals of each stakeholder and the benefit that they perceive the state-level HIE initiative is capable of providing.** Managing and meeting desired benefits is a critical prerequisite to assigning value and securing funding. Foster a collaborative approach to forming the state-level HIE initiative.		
2	**On the basis of the goals and model for the state-level entity, determine start-up organizational funding needs and begin to develop viable sustainability options and/or a business plan**. Consider the feasibility for sustainability from the outset because this may lead to a more realistic assessment of the level of start-up funding needed. For example, multiyear commitments may be sought from start-up funding sources.		
3	**Engage key stakeholders, such as private payers, in the funding discussions early on**. Recognize that HIE is not stand-alone. Find the role for the state-level HIE initiative within the context of the whole state healthcare model. The state-level HIE initiative must be part of a transformed healthcare system that addresses healthcare inflation, healthcare quality, equity, and the roles of individuals, payers, employers, providers, and intermediaries.		

Worksheet 5-1. Principles for Initial Funding (continued)

4	**Seek start-up funding from multiple sources to reduce the risk of reliance on one source and to secure as much seed funding as possible**. Examples of initial funding sources include: (1) federal grants, (2) state funds (e.g., matching grant, bond issue, contract, tobacco settlement funds), (3) Blue Cross/Blue Shield insurance demutualization funds, (4) foundation grants, (5) stakeholder contributions, (6) membership fees from stakeholder organizations, (7) prepayment of subscription or use fees (if applicable), or (8) vendor shares in risk contracts (if applicable). Be sure to understand the practical implications of the state-level HIE initiative's legal entity status and consult with legal counsel on funding opportunities and/or restrictions.		
5	**Seek in-kind services to reduce initial expenses**. Stakeholders could be solicited for assistance in underwriting legal start-up costs; providing expertise, staffing and administrative support, office space, hardware, and networking connectivity (if applicable); and/or HIE infrastructure.		
6	**Seek direct financial support from the state. In addition, secure visible forms of endorsement of the state-level HIE initiative and the importance of its work**. The state-level HIE initiative serves a public good, and the state should contribute to start-up financial support. In addition, forms of endorsement can help the state-level HIE initiative with fundraising from other sources. States do not benefit from competing initiatives at the state level.		
7	**Ensure alignment of grant or contract requirements with the state-level HIE initiative's objectives and vision**. Avoid seeking grants that require activities or consume resources for projects that are not priorities for the organization or that create a challenge for core participants. Also, be cognizant of any strings (restrictions on use of funds, matching fund requirements, etc.) and carefully consider their effect on the organization before deciding to apply for the grant.		

Worksheet 5-2. Possible Sources for Initial Funding

(in no particular order)

POTENTIAL SOURCE OF FUNDING	DETAILS AND CONTACT INFORMATION	EFFORT REQUIRED	MONEY POTENTIAL	ASSESSMENT
Federal grant or contract				
State Matching grant - Bond issue - Contract - Tobacco funds - Blue Cross/Blue Shield insurance demutualization fund - Medicaid waiver savings or reimbursement - State contribution - Other				
Stakeholder contribution				
Foundation grant				
Prepayment of subscription or use fees				
Membership fees				
Revolving loan fund[16]				
Fee for a Board seat				
Other				

[16] Molly Joel Coye and William S. Bernstein, "Improving America's Health Care System by Investing in Information Technology," *Health Affairs*, July/August 2003.

Worksheet 5-3. Principles for Financial Sustainability Models

(in no particular order)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
Technical Operations and Functions			
1	**What functions and/or services or products the state-level HIE initiative will provide will be dependent on and determined by market characteristics**. The state-level HIE initiative must ascertain what services will be saleable, generate revenue in its market, and create value. Proof-of-concept analysis and pilot projects can help reduce risks in deciding whether to roll out a new product or service. Seeking prepayment of fees from customers will also give an indication of the financial viability of the new product or service. Market characteristics can change across time, so careful monitoring will ensure continued viability of the particular service.		
2	**It is better to begin with limited fundamental functions or services for early results and phase in more complex functions incrementally across time**. Demonstrate value early through services that help build the long-term value case. Start out with a basic function of exchanging health information—perhaps even limited to specific types of data (e.g., only medication history) or specific care settings (e.g., only emergency rooms or inpatient treatment). Target high-value data elements to start.		
3	**Long-term funding or sustainability will evolve as HIE functions come online**. Funding levels and mechanisms change with added roles or services and increased efficiency. More HIE services may be able to be added as the clinical record becomes more complete and the data set more rich.		

Worksheet 5-3. Principles for Financial Sustainability Models (continued)

Technical Operations and Functions (continued)			
4	**Business plans and a clear value model should be developed for each HIE function. These plans must be flexible and will evolve as the NHIN develops and other market factors change**. Services that do not provide value will be discarded early by taking this approach. The HIE functions capable of being a sustainable revenue source can be more easily identified and targeted. Consider where the market need is and what services stakeholders could benefit from most. One value to stakeholders could be the convenience of only having to communicate and contract with a single entity, the state-level HIE initiative. Long-term financial sustainability will be achieved only when the state-level HIE initiative succeeds in providing true value to its stakeholders and becomes an indispensable component of the HIE fabric.		
Stakeholder Engagement			
5	**Stakeholders who benefit from state-level HIE initiative services should participate in its funding on the basis of an explicit value model**. The value proposition for elements of HIT must be determined in order to align financial responsibility with the benefit received.		
6	**Provision must be made for supporting the needs of stakeholders who must be engaged or served but who lack the resources to contribute financially**. Allocation of the costs associated with the underserved and/or other stakeholders that are not able to contribute monetarily should be considered when designing the financial model.		
7	**The most effective way to keep stakeholders engaged is for them to have a financial stake in the state-level HIE initiative and/or for the state-level HIE initiative's services to be indispensable to the stakeholder**. Carefully balancing the financial support required with the perceived value and benefit received by the stakeholder is a difficult task. This balance should be reassessed periodically to ensure it remains equitable. Keep in mind that certain stakeholders may be more willing to participate if other types of stakeholders are at the table. The converse may also be true.		

Worksheet 5-3. Principles for Financial Sustainability Models (continued)

Stakeholder Engagement (continued)			
8	**Consider early on how to involve payers in the revenue model**. The number of payers, their market share, type of payer, and the proportion of ERISA plans versus self-funded plans all drive what would be feasible for the state-level HIE initiative. Having a solid understanding of the payer environment and targeting how to leverage and involve payers is critical to the long-term viability of the initiative.		
State and Federal Government			
9	**Strategize on the feasibility of using state and/or federal funding and fully understand the role and obligations for state and federal funding for HIE at the state and local levels**. This relationship is important to understand to avoid any unintended consequences that could affect the local HIE efforts and/or the state-level HIE initiative's plans. For example, the scope of the rights in and to the data and systems may vary because some grants affect intellectual property ownership and rights. Carefully consider whether there will be a competitive edge if a grant is obtained versus the development being funded by the stakeholders.		
10	**The state-level HIE initiative should consider leveraging federal funding to create its state HIE infrastructure, to handle inquiries from other states and to tie in to the federal NHIN, when developed**. In particular, the infrastructure to support public health purposes could be funded with federal grants. However, as noted, it is still important to consider carefully the requirements of any grant and assess its potential effect. In addition, federal reimbursement incentives could be used to help build the HIE infrastructure.		

Worksheet 5-3. Principles for Financial Sustainability Models (continued)

State and Federal Government (continued)			
11	**The state government and the state-level HIE initiative should mutually agree how to bridge their architecture (e.g., Medicaid, public health services, etc.) with the state-level HIE architecture. In addition, the state government may create and/or financially support some of the statewide HIE infrastructure so HIE services can occur**. The state-level HIE initiative and state government working together to collaborate on the development of the infrastructure for statewide HIE and/or capitalizing on state government systems or infrastructure (to the extent feasible and appropriate for the long-term vision) may reduce the overall cost. Certain federal incentives to states for use of HIT (e.g., higher Medicaid reimbursement rates for HIE and waivers allowing the use of Medicaid funds for HIE) can help reduce expenses.		
12	**Be mindful of proposed state and federal policy or legislation that could affect financial models**. Developments around reimbursement policies and incentives may present opportunities to be considered in the financial plan. It is essential that the state-level HIE initiative carefully track and understand the federal agenda so that it will not invest in an effort that may not be eventually feasible or consistent with the federal direction. On the other hand, waiting for federal action before proceeding with state activities may delay HIE progress. Consider using national fiscal intermediaries in supporting the state and leverage these connections as the federal agenda evolves.		
Other Sources of Funding and Revenue			
13	**Seek in-kind or discounted services to reduce ongoing expenses**. Also a principle under the initial funding section, obtaining continuing long-term commitment for in-kind or discounted services will benefit the financial model. If appropriate, consider requiring certain minimum service levels and entering into a contract to document the arrangement, with advice of counsel.		
14	**Identify risks and rewards of various sources of revenue**. Inventory and monitor disruptive technologies or business competitors that could overturn your sustainability.		

Worksheet 5-3. Principles for Financial Sustainability Models (continued)

Other Sources of Funding and Revenue (continued)			
15	**The state-level HIE initiative must balance its need for financial sustainability with local HIE efforts to ensure that its activities complement, rather than compete with or undermine, the financial models of the local HIE efforts, to the extent possible. The state-level HIE initiative should also allow the local HIE efforts to leverage their existing investments and infrastructure to the greatest extent possible**. Careful thought around potential overlap with local HIE efforts allows the state-level HIE initiative to establish the funding stream needed for operations and services, while not supplanting the regional or local HIE activities. The state-level HIE initiative should work collaboratively with the local efforts to assist them in removing barriers to HIE and in scaling up and expanding the local efforts.		
16	**Grants may supplement but are unlikely to be a viable source for ongoing funding**. Grants are useful for testing new ideas or for seed funding; however, care must taken to ensure that a sustainable revenue stream is developed to support the effort. That is, avoid seeking a grant to develop a new service that no one would be willing to pay for. This situation can be avoided by getting a commitment up front from the targeted stakeholders who will eventually be paying for the service. In addition, the focus of the grant should fit into the overall vision for the state-level HIE initiative and not distract it from its long-term goals. Note that grant proposals are different from business plans, and a true business plan is recommended for each new service or product contemplated.		

Worksheet 5-4. Potential Revenue-Generating Services or Products – TECHNOLOGY OPERATIONS

(in no particular order)

POTENTIAL SERVICE	BENEFIT TO PATIENT CARE	NONMONETARY VALUE TO OTHER STAKEHOLDERS*	SOURCES OF REVENUE	MONETARY POTENTIAL	INVESTMENT AND EFFORT REQUIRED	TIME TO MARKET	PRIORITIZATION
Clinical data: providing virtual health record for a patient at point of care (e.g., in the emergency department)							
Clinical data: clinical messaging							
Clinical data: e-prescribing							
Clinical data: medication history							
Clinical data: push certain discharge or other patient data to Primary Care Physician							
Clinical data: disease management							
Clinical data: decision support							
Reporting of positive laboratory results required by public health							
Pay-for-performance reporting							

Worksheet 5-1. Potential Revenue-Generating Services or Products – TECHNOLOGY OPERATIONS (continued)

POTENTIAL SERVICE	BENEFIT TO PATIENT CARE	NONMONETARY VALUE TO OTHER STAKEHOLDERS*	SOURCES OF REVENUE	MONETARY POTENTIAL	INVESTMENT AND EFFORT REQUIRED	TIME TO MARKET	PRIORITIZATION
Other aggregate data reporting							
Administrative data: eligibility checking							
Administrative data: credentialing data exchange							
Web portal services							
Patient portal							
Data and application hosting services (e.g., application service provider)							
Application vendor service (e.g., provide and implement electronic medical records [EMRs])							
Data storage services (e.g., backup site)							
Connectivity services (e.g., Internet service provider)							
Data analysis							
Research							
Other secondary uses of the data†							

* See ***Worksheet 2-1 in Appendix B*** for examples of other stakeholders to consider. One stakeholder's gain may be another's loss, so the effect of proposed services on all stakeholders should be assessed.

† There may need to be more policy development around secondary uses of the data.

Worksheet 5-5. Potential Revenue-Generating Services or Products – NO TECHNOLOGY OPERATIONS

(in no particular order)

POTENTIAL SERVICE	BENEFIT TO PATIENT CARE	NONMONETARY VALUE TO OTHER STAKEHOLDERS*	SOURCES OF REVENUE	MONETARY POTENTIAL	INVESTMENT AND EFFORT REQUIRED	TIME TO MARKET	PRIORITIZATION
Educational services and materials							
Technical assistance to local HIE efforts							
Grant writing services							
Grants and contracts administration services							
Staffing resource for local HIE efforts							
Implementation support for local HIE efforts							
Group purchaser of HIT							
Other							

* See ***Worksheet 2-1 in Appendix B*** for examples of other stakeholders to consider. One stakeholder's gain may be another's loss, so the effect of proposed services on all stakeholders should be assessed.

Worksheet 6-1. Principles for HIE Policy Development

(in no particular order)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
Advocacy, Education, and Collaboration			
1	**Creating or fostering a culture of collaboration will reduce barriers to statewide HIE**. The creation of a state-level HIE initiative entity will not necessarily result in or ensure statewide HIE. A critical mass of stakeholders must collaborate to sustain HIE efforts long term. In addition, remember that collaboration can originate from self-interest.		
2	**Education early and often will alleviate much fear and uncertainty in sharing healthcare data—specifically, education about what is permitted by privacy law**. There are many misperceptions and misunderstandings about the scope of privacy laws (especially Health Insurance Portability and Accountability Act [HIPAA]) that create fear and hesitancy to participate in HIE. When properly educated, stakeholders understand that HIPAA (and many state laws) allow for fairly generous exchanges of health data for the fundamental purposes of most HIE activities, such as patient treatment. Stakeholders (including consumers) may need to work through concepts together to come to common interpretations and shared understandings of applicable laws and barriers, in addition to formal education on HIE issues.		
3	**Seek broad and bipartisan political support. Be aware of political forces and agendas within the state**. Approach both parties to educate and gain support for statewide HIE efforts and to lower barriers to HIE policies. Consider carefully whether to use the governor to announce or lead the charge for support because the governor is by nature aligned with one political party. Seek support from a broad range of interested parties for HIE initiatives, keeping in mind that roles change within a state government and that state government personnel may leave for the private sector and be in a position to provide support there.		

Worksheet 6-1. Principles for HIE Policy Development (continued)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
Advocacy, Education, and Collaboration (continued)			
4	**Education early and often about the value and benefits of HIE were noted to be essential**. It is important for the governing body and all HIE participants, including consumers, to have a solid understanding of the benefits of secure HIE.		
Legal and State Policy Barriers			
5	**State-level HIE initiatives can play an important advisory role to help create legislation or Executive Orders to remove HIE barriers**. Presumably, a state-level HIE initiative will convene the state's greatest champions for HIE and thus will be able to serve as a clearinghouse and facilitator for educating public officials about the advantages of HIE and the necessity of removing barriers. Consider whether state-enabling legislation will give legitimacy to the state-level HIE initiative.		
6	**Recognizing that state policy also gets implemented through state contracts, the state-level HIE initiative could assist state government in creating model contracts for the state government to use with other HIE stakeholders**. The role of the state-level HIE initiative as a neutral, multi-stakeholder entity will assist in harmonizing the interests of the varied stakeholders.		
7	**Start early to identify barriers to minimize their effect on state-level HIE initiative plans**. Identifying barriers early is critical to prevent major roadblocks after operational plans have already been developed and to avoid reworking those plans.		
8	**Engage an attorney early on to help identify legal barriers before planning begins**. Legal considerations should be addressed at the outset before technology and operations are implemented that require legal compliance. For example, state law that places restrictions on sharing certain types of data should be considered and addressed when designing the system. Another example is a state law that requires any entity receiving a certain amount of its funds from state grants to be subject to open records law, which could seriously jeopardize the operations if all patient data are public record.		

Worksheet 6-1. Principles for HIE Policy Development (continued)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
Legal and State Policy Barriers (continued)			
9	**Structure the state-level HIE initiative's activities to be able to adapt when state or other law changes, when market forces exert pressure, and when standards or certification requirements change**. Changes in law and in the market are inevitable, and state-level HIE initiatives must be flexible enough to adjust to accommodate such changes. Recognize inconsistencies between and among state and federal laws and standards. Also, be aware of unusual state and federal contracting cycles. Finally, flexibility is needed to account for differences in states' laws to accommodate interstate populations, especially in border areas.		
Technology and Operations			
10	**Ensure that IT and health information professionals and those who understand the practicalities of sharing data are engaged when developing plans for operations or setting standards. Use technical and legal workgroups to reach good solutions and consensus on policies**. Their involvement will help assess the effect of HIE policy choices on IT development and implementation time lines and costs.		
11	**Work on HIE policies at the same time as operations and technology are being designed to ensure that the HIE policies are reflected in the resulting design and that the HIE policy is feasible to implement**. Policies, operations, and technology are interdependent and must be considered simultaneously. Policies should also align with governance principles of the state-level HIE initiative.		
12	**Focus first on HIE policies for types and uses of data that are easier to gain consensus on (e.g., for treatment at point of care)**. Tackle secondary uses of the data that may be more controversial or more subject to scrutiny (e.g., research use, quality improvement, healthcare operations) after initial trust among the parties is solidified.		

Worksheet 6-1. Principles for HIE Policy Development (continued)

	PRINCIPLE	IMPORTANCE IN MY STATE	ISSUES TO CONSIDER IN MY STATE
Technology and Operations (continued)			
13	**Consider and ensure consistency with national standards, formats, and certifications (such as recognized and widely used code sets).** Failure to create policies consistent with national standards and certifications will discourage stakeholders from participating for fear of not being able to be "certified" and for fear of not being able to share data using common code sets and formats (thus inhibiting efficient HIE).		
14	**Privacy practices should comply with state and federal law, take into account stakeholders' respective positions, and reflect the key stakeholders' consensus**. Consider the state-level HIE initiative's planned activities when evaluating alternatives for privacy practices. The development of privacy practices are influenced by various factors, such as culture and attitude toward privacy, stakeholder positions, implications for technology and financial model, and liability risk. For example, a "record locator service" data model may be chosen to reflect stakeholders' concerns over a centralized database. Privacy practices should be driven by the state-level HIE initiative's governance process. Remember that consumers are also stakeholders in HIE policy.		
15	**Reevaluate each HIE policy periodically to assess whether the policy is helping or inhibiting achievement of the HIE mission**. Look at whether privacy policies are too restrictive. Evaluate if the policies are allowing the HIE to get populated with enough data to be useful and look at whether the right people are able to get access to the right data to treat patients.		

Worksheet 6-2. Sample HIE Barriers and Possible Solutions to Consider

(in no particular order)

NO.	POTENTIAL PRACTICAL AND LEGAL BARRIERS TO HIE	POSSIBLE SOLUTION	BARRIER IN MY STATE?
1	Rural communities and smaller providers unable to afford the interface necessary to participate in an HIE	Negotiate a statewide agreement with a vendor. Public health may be able to play a role to connect smaller providers (e.g., in connection with enabling rural communities to report communicable diseases electronically or to do biosurveillance).	
2	Rural communities without reliable Internet access	Federal funding out of the telecommunication act may be available at the federal level. Other federal agencies have earmarked dollars for rural health. Local philanthropic organizations may also be willing to fund rural needs.	
3	Antitrust concerns (restraint of trade or collusion)	Transactions can be structured to avoid it, especially if doing it for the good of the community. This is not really a barrier, just something to consider. If stakeholders come together to do volume purchasing, it is more of a concern. It may not be a barrier if they are not sharing pricing or financial data.	
4	Restrictive state privacy laws	Medication history issue in one state prohibited payers from sharing medication history related to HIV, and so on. The problem was solved by obtaining medication history from someone other than the payer. State privacy laws may require technical or operational solutions to obtain and track patient consent to exchange health information. In extreme cases, HIE may need to exclude certain classes of data (e.g., mental health) or data from certain kinds of stakeholders (e.g., communicable disease information from a Department of Health).	

Worksheet 6-2. Sample HIE Barriers and Possible Solutions to Consider (continued)

NO.	POTENTIAL PRACTICAL AND LEGAL BARRIERS TO HIE	POSSIBLE SOLUTION	BARRIER IN MY STATE?
5	Stark Exceptions, Anti-Kickback Statute Safe Harbors	Legislation is pending in Congress that could provide broad protections from the Anti-Kickback Statute and the Stark Law for donated technology. The OIG has promulgated final regulations that provide limited safe harbors for the provision of software and hardware for e-prescribing and software for EHRs. CMS has promulgated limited exceptions under the Stark Law that generally track the OIG safe harbors. Arrangements, such as regional consortia to provide hardware and software for EHRs, can be structured that would not implicate the federal Anti-Kickback Statute or the Stark Law. Be aware that some states passed their own versions of similar, more stringent laws.	
6	Public or open records law	The state-level HIE initiative can seek a legislative or regulatory exception for HIE (but may argue that HIPAA preempts state open records laws). Exceptions should be considered for (at least) trade secrets, health data, financial data, and proceedings of the organization.	
7	Administering special protections for special categories of data (e.g., mental health, HIV, drug and alcohol abuse)	Submitting participants may need to be required to filter data to avoid sending it to the state-level HIE initiative. Data can be filtered at the state level, but the cost of filtering the data must be considered, as well as the liability of the state-level HIE initiative if the filtering mechanism fails. The state-level HIE initiative must carefully consider whether its scope should include these types of specially protected information, at least initially. Taking on these special problems can cause debate and delay in a start-up organization.	
8	Unwillingness to share data across local HIEs because of competition or disagreements	Emphasize the importance of exchanging patient data for treatment purposes (which providers have traditionally done in a paper-based system for decades). Place limits at the organization level through data-use agreements that prevent competitors' financial and proprietary data from being used in any form other than an aggregate form that does not identify specific entities (or place blanket restrictions on aggregating the data at all). These kinds of issues can typically be addressed through carefully defining permissible uses and disclosures of data submitted to the HIE initiative.	

Worksheet 6-2. Sample HIE Barriers and Possible Solutions to Consider (continued)

NO.	POTENTIAL PRACTICAL AND LEGAL BARRIERS TO HIE	POSSIBLE SOLUTION	BARRIER IN MY STATE?
9	Fear of malpractice liability (e.g., what is it going to do to the standard of care)	The potential for HIE to raise the standard of care can be a concern; if more data about a patient's history is easily and widely available, it is realistic to expect that the standard of care will require providers to access and consider it (although one could argue that a provider that does not obtain a patient's prior history in our current paper-based system is already violating a standard of care). This situation actually presents at least two arguments to convince providers to adopt HIE: (1) HIE is coming, therefore adopting it and participating in HIE will help the provider keep up with the standard of care; and (2) to the extent that getting a patient's medical history is already the standard of care in a paper-based world, participating in HIE will get the provider the records much more quickly and better treatment decisions can be made (thus, potentially lowering malpractice liability that occurs when a provider provides treatment in the absence of prior medical records because of the delays inherent in exchanging paper records).	
10	Fear of liability for sharing data with someone in violation of privacy laws For example: - Lack of understanding, if the law permits it - Lack of clear guidance on state laws, if the law is ambiguous - Actually violating the privacy laws by making an error	Legally compliant exchange policies and education are the primary solutions to this issue. First, legal counsel should be engaged to ensure that all relevant state and federal privacy laws are incorporated into HIE policies. Second, education (whether through brochures, training sessions, online information, etc.) should be provided to HIE participants to provide assurance that the HIE initiative and its participants are permitted by law to exchange data for treatment (or whatever purposes it is legally permitted to pursue). After legally compliant policies and education, participants may find security in narrowly drawn data exchange agreements, indemnification obligations among the participants, and the ability to withdraw from the HIE initiative.	
11	Payer or provider differences of perception and disagreement	Providers are frequently reluctant to share data with payers because of the perception that the payers will use the data to their detriment regarding reimbursement. Mutually advantageous uses of data for quality should be reached by consensus.	

Worksheet 6-2. Sample HIE Barriers and Possible Solutions to Consider (continued)

NO.	POTENTIAL PRACTICAL AND LEGAL BARRIERS TO HIE	POSSIBLE SOLUTION	BARRIER IN MY STATE?
12	Fear of being subjected to data breach notification laws that may cause administrative and financial burdens for compliance (e.g., if there is a security breach, the HIE initiative may be required to do a mailing to patients whose data was compromised under some states' laws)	The state-level HIE initiative must carefully analyze state laws about data breach notification and develop policies and procedures for complying when breaches occur (assuming the laws apply to the kinds of data the HIE initiative exchange in the first place). Careful attention must be paid to which entity actually has the notification obligation under state laws (the HIE initiative itself or the entities that submitted the data to the HIE initiative). Organizations should consider clearly defining and apportioning these obligations (and the associated costs) in data-exchange agreements. HIE initiatives must also consider the data breach notification laws of other states if its HIE contains data on patients from other states. Legal analysis is required to determine the "long-arm" applicability of one state's notification law on an HIE initiative in another state.	
13	State legislators or other elected officials raising concerns owing to lack of understanding	Help educate to ensure they grasp the value.	
14	Lack of understanding of other stakeholders	Help educate to ensure they grasp the value.	
15	CHIN failure memories and hesitation	Efforts a number of years ago to create Community Health Information Networks (CHINs) failed for a number of reasons that have been written about by several authors.	
16	Perception that the restriction that Medicaid data may only be used for state plan administration would prohibit it being used for the treatment of non-Medicaid patients if shared through an HIE initiative	Use of Medicaid data is both a real and perceived barrier that must be addressed on a state-by-state basis. One state's Medicaid office took the position that it cannot share claims data with a non-Medicaid provider, whereas another state's Medicaid office was comfortable sharing data for treatment purposes—even after the patient was no longer a Medicaid recipient. Use of Medicaid data for research requires more approval and a close link showing the benefit of the research to Medicaid and its recipients. Allowing use of Medicaid data in an HIE initiative has the benefit of literally creating a record for the uninsured.	

Worksheet 6-2. Sample HIE Barriers and Possible Solutions to Consider (continued)

NO.	POTENTIAL PRACTICAL AND LEGAL BARRIERS TO HIE	POSSIBLE SOLUTION	BARRIER IN MY STATE?
17	Doctors delaying EHR adoption or financial or concerns about the effect on work flow	EHRs certified by the Certification Commission for Health IT (CCHIT) may accelerate adoption.	
18	Clinician resistance to work flow changes slowing the adoption of EHR systems in physician offices	HIE initiatives could share time estimates on work flow effect with doctors.	
19	Providers with existing systems and EMRs resistant to using a new system	The release of CCHIT certification standards should help alleviate some of these concerns. Physicians should be educated about benefits of HIE and how HIE could eventually save money in terms of efficiency of electronic (versus paper) records, speed of getting results (e.g., clinical messaging), and arguments that malpractice liability might be lowered. Finally, alternative funding solutions might be sought to help physicians pay for the cost of EMRs (see the "Initial Funding and Financial Model for Sustainability" section on funding).	
20	Physician with little incentive to invest in EMR because of capitation, if Managed Care Organizations are prevalent	There is little incentive for the physician to make financial investments in technology, if his reimbursement rates are capitated.	
21	Lack of bipartisan approach if governor announces the initiative and the groundwork has not been done ahead of time to engage and involve both political parties	Engage both political parties' support and educate early on HIE. Stress that this not a partisan political issue but rather a bipartisan (or, better, nonpartisan) effort to improve everyone's healthcare.	

Worksheet 6-2. Sample HIE Barriers and Possible Solutions to Consider (continued)

NO.	POTENTIAL PRACTICAL AND LEGAL BARRIERS TO HIE	POSSIBLE SOLUTION	BARRIER IN MY STATE?
22	Steady drumbeat of new stories of security breach of medical data	Adverse public relations is always a challenge; however, with regard to stakeholders, steps can be taken to create and maintain confidence in the HIE initiative. First, the HIE initiative should have comprehensive HIPAA-compliant security policies (and follow them) and make the policies available for stakeholder review. Those policies should include disaster plans for responding to and mitigating security breaches. The policies should also address who can have access to the data and when (e.g., only when a particular patient is actually under the active treatment of a physician or is actually a patient in a hospital). The HIE initiative could perform an annual security audit by an independent third party and make the results of the audit (and any remedial measures taken in response to the audit) available to stakeholders. The data exchange agreement might address some of these concerns through indemnification provisions and, perhaps, by providing participants in the HIE initiative an opportunity to conduct their own audits of the HIE initiative's practices upon good cause.	
23	Lack of consumer understanding	Consumer education is important and should be directed to all groups that might fall under the broad definition of "consumer" (e.g., privacy advocates and everyday healthcare users—understand that these two groups might not have the same interests and that they do not necessarily speak for one another). Perhaps convene a consumer group with all different types of consumers. Gain the interest of local television stations' and newspapers' health-beat reporters to do positive stories on the benefits of HIE. Consider whether to give consumers the right to obtain their own health record directly from the HIE initiative.	

Worksheet 6-2. Sample HIE Barriers and Possible Solutions to Consider (continued)

NO.	POTENTIAL PRACTICAL AND LEGAL BARRIERS TO HIE	POSSIBLE SOLUTION	BARRIER IN MY STATE?
24	Privacy practices that are not required by law but that are institutional policies of the participating healthcare entities or stakeholders	An HIE initiative needs to strive for consistency in the uses and disclosures of data and in the standards related to the data. Data submitted by entities that have privacy policies that are more stringent than legally required can cause the HIE initiative to treat that entity's data in a more protective manner than data from other sources (e.g., some entities may not allow their data to be used for research purposes or for healthcare operations of other entities; some entities may liberally grant patient-requested HIPAA restrictions). This issue adds cost, burden, and risk to HIE initiative administration. HIE initiatives should educate participants on the need for consistent privacy practices and then work with them to try to get the Notice of Privacy Practices or other policy changed. In the event that change cannot be accomplished, the HIE initiative must ensure that it is operationally and technologically capable of providing the extra protections to that particular entity's data.	
25	Family Educational Rights and Privacy Act (FERPA) restrictions on obtaining health data from school nurses	FERPA (20 U.S.C. § 1232g; 34 CFR Part 99) is a federal law that protects the privacy of student education records (including health data collected by the school nurse). The law applies to all schools that receive funds under an applicable program of the Department of Education. Generally, schools must have written permission from the parent or eligible student to release any information from a student's education record. There are some exceptions, but none currently for health data that could be useful to public health officials or other healthcare professionals.	
26	ERISA	ERISA preempts state regulation of employer benefits. As a result, states may find it difficult to impose requirements or assessments that affect self-insured health plans. When looking at the environment of health insurers in any state, it is important to understand how actions taken will affect ERISA-qualified plans versus non-ERISA plans. Regulations or other actions may affect each type of payer differently and may put one type at a disadvantage versus another. Thus, the effect of ERISA should be considered when evaluating the payer environment.	

Worksheet 6-3. Sample HIE Data Sharing Agreement Issues

(in no particular order)

ISSUES FOR CONSIDERATION	APPROACH
Who has access to the data and under what conditions (including any exceptions like a break-the-glass policy)?	
Will a certain subset of data be required to be contributed or shared in order to participate?	
For what purposes may the data be used (treatment, payment, healthcare operations, research)?	
Are there defined standards or formats that the data must comply with for sending or receiving?	
What exact data elements will be shared (e.g., payers see only aggregated data for a provider)?	
Will the agreement contain indemnification provisions?	
Will participants have the right to audit the HIE initiative for security or financial reasons (e.g., trigger for audit, maximum frequency, who pays, confidentiality of resulting report, require independent third party to conduct the audit, action to be taken after the report)?	
How will the parties address privacy requests and privacy model (requests for restrictions, opt out, opt in)?	
What can be done with the data after a participant withdraws or terminates?	
Who can withdraw and under what conditions?	
Can participants be expelled? Is so, for what reasons?	
What are the criteria for participating in the HIE initiative?	
What fees or other compensation will be required?	
Are there tiered levels of participation?	
What specific services or products are included?	
Is there a service level agreement (e.g., minimum availability of the network, response time)?	
What are each party's responsibilities?	
Who will do training and support?	
How will security breaches be handled? Who has responsibility for reporting under state data breach notification laws?	

Worksheet 6-3. Sample HIE Data Sharing Agreement Issues (continued)

ISSUES FOR CONSIDERATION	APPROACH
How will the HIE initiative protect participants' proprietary data (e.g., practice patterns, charges)?	
Approval process for new uses of the data that arise	
Will the state-level HIE initiative be a business associate of covered entity participants? If so, how will HIPAA's patient rights (restriction, access, accounting, amendment, etc.) be administered by the state-level HIE initiative on behalf of the participants?	
Who enters into the data-sharing agreement (e.g., do not require hospital-based clinicians to sign agreement with HIE initiative, but do have hospitals sign agreement and make hospitals responsible for clinicians' training and use of HIE's products or services)?	
Will the agreement contain liability disclaimers and/or a cap on damages?	
What remedies will be available for breach? Injunctive relief? Money damages?	
Who will own intellectual property associated with the HIE initiative?	

Worksheet 6-4. Role in Determining Data Model

(in no particular order)

ROLE OF STATE-LEVEL HIE INITIATIVE IN DETERMINING DATA MODEL	**PROS**	**CONS**	**FEASIBILITY**
Intimately involved in deciding on data model			
Convenes and defers to experts to decide on data model			
Determines use cases and business requirements, then contracts with vendor to execute			
Requests (e.g., RFI) data model solutions from vendors			
Defers to local HIE efforts for guidance (if multiple effort model)			

Appendix C—Tables

Table 1. State-Level HIE Initiative Governance Composition Comparison

Because the members are actually in more than one category (e.g., a hospital is also an employer), the categorization in this chart is based on the member's primary role or viewpoint contributed to the governing structure. This chart is current as of August 8, 2006.

Governance	State								
	CA: CalRHIO Board of Directors	**CO: CORHIO Pre-Board Steering Committee**	**FL: Governor's Health Information Infrastructure Advisory Board**	**IN: Two Organizations (1) IHIE Board of Directors (2) INPC Management Committee**	**MA: MHDC Board of Directors**	**ME: HealthInfoNet Board of Directors**	**RI: RIQI Board of Directors**	**TN: Governor's eHealth Advisory Council**	**UT: UHIN**
Type of legal entity	501(c)(3)	Anticipate 501(c)(3)	Governor's Advisory Board. Note: FHIN, Inc. will be created as a 501(c)(3)	IHIE: 501(c)(3) INPC: virtual (no legal entity)	501(c)(3) (also note that MA-SHARE is a sole member LLC subsidiary of MHDC)	501(c)(3)	501(c)(3)	Governor's advisory council	UHIN is in the process of applying to become a 501(c)(6). Currently it is a state nonprofit and a federal for-profit.
Number of governing or voting members or directors	22	41 on Steering Committee. Board of Directors to be determined.	12 members appointed by the governor	IHIE: 15 INPC: 7	25	19	22	17 members appointed by the governor	16, however many members represent more than one "type."

Governance Composition	State								
	CA	CO	FL	IN	MA	ME	RI	TN	UT
Hospitals	3 members: including healthcare associations	6 members: major profit or nonprofit systems, specialty, public, hospital association	3 members	IHIE: 5 members INPC: 5 members	1 member: Massachusetts Hospital Association	4 members: CEO of 3 large hospital systems, and one rural hospital	4 members: CEOs of two largest IDNs, a CEO of a community hospital and the hospital association	2 members	6 members: major profit or nonprofit systems, specialty, public, hospital association
Physicians	3 members: including medical associations	4 members: professional association, large medical groups, primary care practitioner	5 members are physicians, plus 1 dentist and 1 pharmacist	IHIE: At least 4 on IHIE Board (including 2 medical societies), plus several other physicians INPC: One group practice	4 physicians plus Massachusetts Medical Society and Massachusetts Nurses Association	3 members: CEO of ambulatory physician center, hospital Chief Medical Officer, hospital Chief Medical Officer or Chief Information Officer	4 members: all practicing; CEO of largest group practice in Rhode Island	1 member: mental health provider	3 members: including medical association
Payers	3 members	3 members: health plan association, Kaiser, Children's Basic Health Plan	2 members	None, but they are becoming more involved now	3 members	1 member	3 members, not including government	1 member	12 members (also see "Gov't")
Employers	1 member	4 members including Colorado business group, state department of personnel, Colorado Chamber of Commerce	No participation	1 member on IHIE Board is from an employers' forum group	3 members	1 member	1 member	4 members	No partici-pation

Composition (cont'd)	State								
	CA	CO	FL	IN	MA	ME	RI	TN	UT
Government	3 members: CMS, California Department of Health, the Managed Risk Medical Insurance Board	3 members, including Public health, CMS	Not officially a member, but the Governor's Advisory Board advises the Agency for Health Care Administration, which is charged with implementing EHRs, and which in turn advises the governor, speaker of the house, and president of the senate on legislative recommendation	IHIE: 2 members: Indiana State Department of Health, Marion County Health Department are on IHIE Board INPC: None	4 members: Massachusetts Department of Public Health, Massachusetts Group Insurance Commission, Information Technology Division, and Board of Registration in Medicine	3 members: HHS, Maine CDC, governor's office	4 members: Rhode Island HHS, Rhode Island Department of Health, lieutenant governor, Rhode Island health insurance commissioner	2 members: 1 represents Bureau of TennCare (Medicaid), chair of the eHealth Advisory Council	2 members: Utah Department of Health (Medicaid), Public Employee Health Plan, plus 2 ex officio members: Insurance Commis-sioner and state Chief Information Officer
Researchers or academia	1 member: Research and Education organization	4 members from the university	2 universities	IHIE: Regenstrief and the Indiana University School of Medicine INPC: Regenstrief is on the INPC management committee	1 member	1 college of osteopathic medicine	1 member from Brown University	1 member	1 member
Consumers	2 members: American Association of Retired Persons and 1 organization representing the consumer voice	3 members: consumer health initiative, Colorado Office of Rural Health, Colorado Children's Campaign	No participation	No participation	2 members	2 members: Executive Director of the National Alliance for the Mentally Ill, private consumer	2 members: Executive Director of Consumer Advocacy organization and Community Health Center Patient	1 member	No partici-pation.

Composition (cont'd)	State								
	CA	CO	FL	IN	MA	ME	RI	TN	UT
Quality improve-ment organization	1 member	2 members	No participation	No participation	1 member	No participation	1 member	No participation	1 member (state QIO: Health-Insight)
Local HIE effort	1 local HIE effort	6 members	No participation	IHIE and INPC grew out of the local effort to be statewide in scope. There are some smaller HIE efforts in the state, but none are on the IHIE Board or on INPC.	No participation	No participation	No local HIE	3 members	No partici-pation - however, UHIN connects to several local networks including Inter-mountain's
Vendors	No vendors	No vendors	No vendors	None, except Regenstrief is also a "vendor" to IHIE	No vendors	No vendors	No vendors	1 vendor	No vendors
Out-of-state expert	No participation	No participation	1 member	No participation	No participation	No participation	No participation	1 member	No partici-pation
Other	2 members: 1 Integrated Healthcare Association, 1 organization working with rural and underserved populations	6 members: nursing association, community clinics, clinical guidelines collaborative, attorney, Agency for Healthcare Research and Quality (AHRQ) grant primary investigator	No participation	IHIE: 2 members: BioCrossroads is economic force and financial supporter of life sciences; Indianapolis mayor INPC: none	4 members: 1 labor union, 1 MHDC supporting member, 2 at-large individuals	4 members: 2 business leaders, 1 legislator, 1 public health professional	1 from Business Community; 1 attorney, 1 Pharmacist,. Will be adding a nurse and a mental health representative	1 member: pharmaceutical company	1 member: Utah Group Managers Association (ex officio)